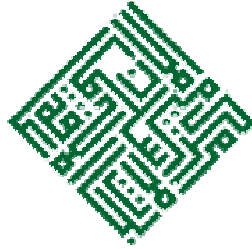


مركز الأمير سلمان لأبحاث الإعاقة  
Prinze Salman Center for Disability Research

**PRINCE SALMAN CENTER  
FOR DISABILITY RESEARCH**

**REPORT ON THE ACTIVITIES  
OF THE YEAR 2002**



مركز الأمير سلمان لأبحاث الإعاقة  
Prince Salman Center for Disability Research

## **THE MISSION OF THE PRINCE SALMAN CENTER FOR DISABILITY RESEARCH IS:**

- TO BE A CENTER OF EXCELLENCE IN DISABILITY RESEARCH.
- TO CONDUCT AND SUPPORT RESEARCH WHICH CREATES KNOWLEDGE ABOUT HUMAN DEVELOPMENT AND DISABILITIES.
- TO IMPROVE THE QUALITY OF LIFE FOR PERSONS WITH DISABILITIES AND TO ENABLE THEM TO REACH THEIR FULL POTENTIAL.

**A MESSAGE FROM  
H.R.H. PRINCE SALMAN BIN ABDULAZIZ**

The issue of disability and its social and economic repercussions constitutes one of the most important challenges facing contemporary societies at present. One of the most effective means to deal with this issue is to investigate the causes of disabilities. In addition, overcoming obstacles that constrain people with disabilities and limit their productivity and independence in society are worth studying.

The Center, which is motivated by religious and humanitarian concerns for persons with disabilities, is a major contribution to the Kingdom of Saudi Arabia and its benevolent society. The Center has adopted plans and ambitious goals which will be realized at the hands of highly qualified personnel.

God willing, this blessed institution will seek to mobilize all the useful resources that can serve the multiple interests of people with disabilities, our religion, our nation, and humanity at large.

**H.R.H. PRINCE SALMAN BIN ABDULAZIZ**  
President - Founder of the  
Prince Salman Center for Disability Research

**A MESSAGE FROM  
H.R.H. PRINCE SULTAN BIN SALMAN BIN ABDULAZIZ**

The Prince Salman Center for Disability Research was established to address the real and important needs of persons with disabilities and their families. In addressing those needs, the PSCDR has set its goal as the promotion, conduct and support of scientific research and the application of new knowledge to the benefit of persons with disabilities and their families.

We believe the PSCDR has a great opportunity to advance the causes of persons with disabilities. In addressing that opportunity, the PSCDR will undertake basic and applied research projects in the biological, behavioral and social sciences; it will promote and develop collaborations with scientists both within the Kingdom and world-wide; and it will collect and disseminate information through all media including the Internet.

We hope the PSCDR will advance new insights into the causes of disabilities and develop new strategies to prevent them, or reduce their impact on an individual. We further aspire to a time when new knowledge created by research will lead to more effective service and support systems for persons with disabilities and their families.

At the PSCDR, we stand ready to move forward into the future with expectations for important accomplishments and renewed spirits. That future holds great promise for all of us, including persons with disabilities, God willing.

**Prince Sultan bin Salman bin Abdulaziz**  
Chair, Board of Trustees  
Prince Salman Center for Disability Research

**A MESSAGE FROM  
Stephen R. Schroeder, Ph.D.**

The next decade holds the promise of being the most exciting and productive in the history of research on disabilities. If we capitalize on the advances in research on genetics, neuroscience, and behavior over the past 30 years, we will be able to integrate these advances into a biobehavioral approach that will allow us to eradicate or prevent many of the disabilities that have puzzled our ancestors for centuries. Technology already exists to prevent most of them. Research now has to develop them, perfect them, make them cost-effective and ethically acceptable to the public.

The role of the Prince Salman Center for Disability Research is to ensure that the Kingdom of Saudi Arabia and the Middle East take a lead role in making this revolution happen for its people with disabilities and their families. Best practices must be based on a strong validated research foundation. The Prince Salman Center has been organized to provide this function for the Kingdom.

The 2002 Report in the following pages describes the organization, the functions, and the progress toward our goals. A substantial beginning has been made, but much remains to be done before The Prince Salman Center takes its rightful place in the international community of scholars dedicated to improving the quality of life for our brothers and sisters with disabilities. We anticipate that the year 2003 will be one of consolidation and rapid growth toward achieving these goals.

**Stephen R. Schroeder, Ph.D.**  
Executive Director

**PRINCE SALMAN CENTER FOR DISABILITY RESEARCH**  
**REPORT ON ACTIVITIES IN THE YEAR 2002 (G)**

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## EXECUTIVE SUMMARY

This report describes the progress of the Prince Salman Center for Disability Research for the year 2002 (G) and proposes a budget for 2003 (G). This past year has been one of consolidation and expansion of the reorganization of the Center begun in 2001 (G) by the previous Executive Director, Dr. Terrence Dolan. A seamless transition to a new Executive Director, Dr. Stephen R. Schroeder, over spring and summer has been completed. Considerable effort has been spent on developing the infrastructure of the Center in anticipation of its gaining independence from the Disabled Children's Association. All of the tools and procedures are in place now for the Center to function as an independent non-profit organization, once the legal procedures have been completed.

Two intramural research programs have made good progress this past year. The first, involving a collaboration with the King Faisal Specialist Hospital and Research Centre (KFSHRC), is on the molecular genetics of neuromuscular and neurosensory diseases of children in Saudi Arabia. Drs. Bharucha and Hodgkinson have identified a novel form of hereditary spastic paraplegia in a Saudi family showing linkage to chromosome 13q. Their data have allowed them to zero in on a very small region of the chromosome. Their findings are important because they bring us closer to the possibility of gene therapy for this devastating disorder some day. The second intramural project on language norms for Arabic children by Dr. Alaskary is progressing well. Personnel have been hired and trained to collect data; software for language analysis has been acquired and adapted; public awareness events to increase referral of children to the project have been conducted; and data collection is ready to begin. A third intramural research program for newborn screening of endocrine and metabolic disorders by Dr. Rashed was not approved last year, but it is being resubmitted this year for funding in 2003. It is of great significance to the Kingdom in terms of prevention of human suffering as well as savings in terms of the cost of health care. Two other intramural programs, one on autism and one on the epidemiology of rural health, are in the planning stages.

The extramural research program has made excellent progress in two review cycles involving over 25 proposals and over 60 local and international reviewers and, as a result, we are funding nine projects. The subject of these projects ranges across our 10 priorities, from basic research, such as preimplantation genetic diagnosis, to applied projects, such as a computerized Arabic Braille environment, which will allow any visually impaired Arabic speaking person to use any computer anywhere without an interpreter's assistance. Investigators must survive a rigorous blind peer review by some of the leading scientists in their specialty both locally and internationally. The excellent feedback they receive often allows them to revise and improve their proposals and receive an award after resubmission. This process assures that research funded by PSCDR is competitive internationally.

The development of seven core services in support of the research at PSCDR continued this past year. New key recruitments were made in Information Technology, in Library Resources, and in

Research Services. Aggressive recruitment of new key staff continues this coming year. Each of the core services has made progress toward its goals.

Renewed emphasis on fund raising has also occurred this past year. A Development Plan has been written and a goal of SAR 500,000,000 over a five-year period has been set, in order to build a permanent sustainable endowment for the future. Plans for a permanent Development Office are under way for the coming year.

Finally, brief comments about long-term future opportunities at the PSCDR and a list of publications by Center-funded scientists are included in the closing section of the report.

## ARABIC TRANSLATION OF THE EXECUTIVE SUMMARY

### المخلص التنفيذي

يشرح هذا التقرير مدى التقدم الذي أحرزه مركز الأمير سلمان لأبحاث الإعاقة عام 2002م ، وكذلك مقترح الميزانية لعام 2003م . لقد كان العام المنصرم عام اندماج وتوسع لإعادة تنظيم المركز الذي بدأه المدير التنفيذي السابق د. تيرانس دولان عام 2001م ، ومن بعده د. ستيفن شرودر الذي تولى منصب المدير التنفيذي لمركز الأمير سلمان لأبحاث الإعاقة في الربيع . لقد كانت هناك مجهودات هامة لتطوير البنية التحتية للمركز على أساس التوقعات بفصل واستقلالية المركز عن جمعية الأطفال المعوقين ، وعند الانتهاء من الإجراءات القانونية سيكون كل شيء جاهزاً لبدء عمل المركز بصفة مستقلة على أساس أنه مؤسسة غير ربحية .

حدث تقدم جيد في اثنين من الأبحاث الداخلية خلال العام المنصرم . البحث الأول يتضمن تعاوناً مع مستشفى الملك فيصل التخصصي ومركز الأبحاث ، وهو يبحث الأمراض الجزيئية الحسية العصبية والعضلية العصبية التي تصيب الأطفال في المملكة العربية السعودية . وقد قامت الدكتورة / باروشا والدكتور / هودجكنسن بالتعرف على نوع غير مألوف من الشلل السفلي التشنجي الوراثي لدى أسرة سعودية أظهر اتصالات بالكروموزوم (q13) . وقد سمحت لهما المعلومات التي جمعها بتحديد منطقة صغيرة جداً من الكروموزوم ، وهذا الاكتشاف هام لأنه يقترب بنا أكثر من إمكانية العلاج الجيني لهذا الاضطراب المدمر . أما البحث الداخلي الثاني ، فهو عن تطور النطق واللغة لدى الأطفال في المملكة العربية السعودية للدكتورة / العسكري ، وهو يتقدم بشكل جيد . وقد تم تعيين بعض الموظفين وتدريبهم من أجل جمع المعلومات واكتساب وتكييف برنامج لتحليل اللغة ، وكذلك إدارة مناسبات للتوعية الصحية من أجل زيادة عدد الأطفال المحالين للمشروع ، وأصبح كل شيء جاهزاً للبدء بجمع المعلومات .

في العام المنصرم لم تتم الموافقة على البرنامج البحثي الداخلي الثالث لمسح المواليد المصابين باضطرابات الغدد الصماء والاضطرابات الاستقلابية الذي أعده الدكتور / راشد ، ولكن أعيد تقديمه هذا العام من أجل التمويل لعام 2003م . وهو بحث هام جداً للمملكة من الناحية الوقائية ومن ناحية التوفير المادي في الرعاية الصحية . كما يوجد برنامجاً بحث داخلياً آخران في مرحلة التخطيط ، أحدهما عن التوحد والآخر عن الوبائيات الصحية في الريف .

أما بالنسبة لبرامج الأبحاث الخارجية فقد تقدمت بشكل ممتاز خلال دورتي تحكيم شملت أكثر من 25 مقترحاً وما يزيد عن 60 محكماً من داخل وخارج المملكة ، ونتيجة لذلك نقوم الآن بتمويل 9 مشاريع . وتتفاوت مواضيع هذه المشاريع ما بين الأولويات العشر للمركز بما فيها البحوث الأساسية مثل " التشخيص الوراثي قبل الغرس " و البحوث التطبيقية مثل " تقييم وتنفيذ بيئة حاسوبية تفاعلية لخدمة المعوقين بصرياً " وهذا البحث سيجعل بإمكان أي شخص معوق بصرياً ويتحدث اللغة العربية أن يستخدم أي حاسوب في أي مكان بدون مساعدة مترجم .

يجب أن يجتاز الباحثون الرئيسيون تحكيمياً محجوباً دقيقاً جداً يقوم به بعض العلماء الرواد في مجالهم داخل المملكة وخارجها . وتكون المعلومات التي يتلقاها الباحثون الرئيسيون ممتازة لدرجة تسمح لهم بتعديل وتطوير مقترحاتهم وتلقي المنح بعد إعادة التقديم . وتؤكد هذه العملية بأن مركز الأمير سلمان لأبحاث الإعاقة مركز تنافس عالمي .

لقد استمر التطور في سبعة أقسام تدعم البحوث في مركز الأمير سلمان لأبحاث الإعاقة خلال العام المنصرم ، وتم تعيين أشخاص رئيسيين في قسمي تقنية المعلومات والمصادر المكتبية . وسيظل التعيين مستمراً للأشخاص الرئيسيين خلال العام القادم إن شاء الله . وما يزال هناك تقدم في جميع الأقسام باتجاه أهدافها . كان هناك تأكيد وتشديد على زيادة الموارد المالية خلال العام المنصرم ، وقد تم رسم مخطط تطويري ، والهدف هو الارتقاء بالموارد المالية إلى 500.000.000 ريال سعودي خلال فترة خمس سنوات ، وذلك من أجل تشييد وقف خيري دائم وطويل الأمد للمستقبل . وهناك مشاريع لإنشاء مكتب تطوير دائم خلال العام القادم .

وفي النهاية ، تتضمن الفقرة الختامية في هذا التقرير ملاحظات مختصرة عن الفرص المستقبلية طويلة الأمد في مركز الأمير سلمان لأبحاث الإعاقة وكذلك قائمة بالأبحاث المنشورة أو تحت الطبع للباحثين الذين قام مركز الأمير سلمان لأبحاث الإعاقة بتمويل بحوثهم .

## I. OVERVIEW

This is a report of progress at the Prince Salman Center for Disability Research during 2002. Significant progress has been made over the last year. Dr. Terrence Dolan relinquished his position as Executive Director, to take a very challenging position in the U.S. However, he recruited a long-time colleague, Dr. Stephen Schroeder, from the University of Kansas, to replace him on May 1, 2002. The transition has been relatively seamless, and Dr. Dolan remains as a consultant and chair of the Research Committee. This is a crucial committee at the Center, which oversees the review process of the Extramural Grant Program. Dr. Dolan maintains frequent consultative contacts with Dr. Schroeder on the history and development of Center activities.

Some of the major milestones over the last 18 months are:

1. New, full-time management. For the first time in its history, the PSCDR recruited a full-time Executive Director on February 1, 2001. Dr. Terrence R. Dolan was director from Feb.1, 2001 until March 17, 2002. Dr. Stephen Schroeder assumed the directorship in May, 2002.
2. Development of Center-wide Core Services. The Center has developed an effective infrastructure that centers around the operations of several core services. Those core services are the operational backbone of the Center and are responsible for most internal operations and supports. Most employees of the PSCDR are assigned duties in one of these core services.

The Core Services include: an Administrative Core, an Information Technology Core, a Human Resources Services Core, a Fiscal Services Core, a Media Core, and an Outreach and Dissemination Core. Each core is staffed by PSCDR personnel.

3. The expansion and development of an effective Extramural Research Program including the development of an international peer review system and new administrative/management processes. A newly formed Research Committee serves as the focal point for the review of research applications. During the past year approximately 25 research applications were received via a new Internet-based application process and approximately 8-10 new applications were (or will be) supported. Over 60 scientists from throughout the world were used in the comprehensive review processes that were developed. During the previous nine years of the program, approximately nine applications were supported.
4. The development of an Intramural Research Program involving new research programs administered and conducted by the PSCDR. Also for the first time in its history, the PSCDR took on the role of conducting the Center's own research programs. During the first year two programs were initiated, a third remains in development, and several others are in early exploration stages. The two programs conducted during the past year include a nation-wide study on the development of Arabic language in children and a human genetics program. The former program will be valuable in the eventual development of new assessment and intervention tools for developmental language problems in children with disabilities. The latter program

will be valuable in the identification and elucidation of genetic mutations that cause childhood diseases and disabilities in Saudi Arabia.

5. The participation and recruitment of women staff at the PSCDR. During the past year eight women were recruited to join the staff of the PSCDR. Most were previously employed at the King Faisal Specialist Hospital and Research Center and brought valuable experiences and skills to the PSCDR.
6. The increasing awareness of the PSCDR by the international community and the continuing expansion in the participation of scientists from throughout the world. At present, a Scientific Advisory Board is being formed that involves several scientists from the United States and Europe. In addition, several scientists from outside the Middle East have been involved in PSCDR programs, including the development of The Family Village – a global Internet site being developed for use by Arabic-speaking families. As noted earlier, approximately 60 scientists from outside Saudi Arabia are participating in our extramural review programs.
7. The development of infrastructure at the Center has been important, as we prepare for our independence. A Policies and Procedures Manual, a Pattern of Administration Manual, and a Fiscal Operations Manual that describe the management and operating tenets and practices of the PSCDR have been written and submitted for approval. Criteria for Productivity for a Research Center based upon research conducted at top research centers in the U.S. have been written and adopted by the Center.
8. The development of an Executive Management Team (EMT). The internal operations of the PSCDR were significantly aided by the development of an internal management team that meets weekly. The team is comprised of the Heads of each core service, representatives from the Intramural Research Programs, and the Executive Director and Associate Executive Director for Administration. The EMT is responsible for the implementation and monitoring of policies and operating practices within the PSCDR.

## **NEXT STEPS**

The achievements listed above serve as a solid foundation upon which future efforts can be based. Among the more significant challenges facing the PSCDR are:

1. Fund Raising. It is of the most importance to develop financial resources to support the programs of the Center, including both an in-perpetuity endowment and an operating/research fund. A Plan for Development was drafted last September and implementation has begun. A new Office of Development has been proposed and a job description for a Director has been written.
2. Gain Independence. It is also important that the PSCDR become an independent entity whereby the Board of Trustees and the management of the Center have complete autonomy. Progress has been made in drafting a Charter and Bylaws as well as in preparing for fiscal separation from the Disabled Children's Association.
3. Identify and Train Local Leadership. An important goal is to identify a Saudi with appropriate educational training and experiences and to phase that individual into the senior management of the PSCDR. That individual must have a Ph.D. or M.D. degree

and a notable track record in science. A job description for a Deputy Director of the PSCDR has been written and a search is under way for a permanent Executive Director who could take over the Center after training.

### **Management Procedures.**

In addition to the new research programs and the Center's core services, the management functions of the Center have been modified. The primary management functions of the Center are the responsibility of the Executive Director. The Executive Director provides overall leadership, planning, direction, coordination and evaluation of the Center's programs and administration. The Executive Director is aided by a new committee, the Executive Management Team (EMT). The EMT is comprised of the heads of each of the intramural research programs and the heads of the core services. The duties of the EMT, which meets weekly, include advising the Director on all matters of policy and practices within the Center.

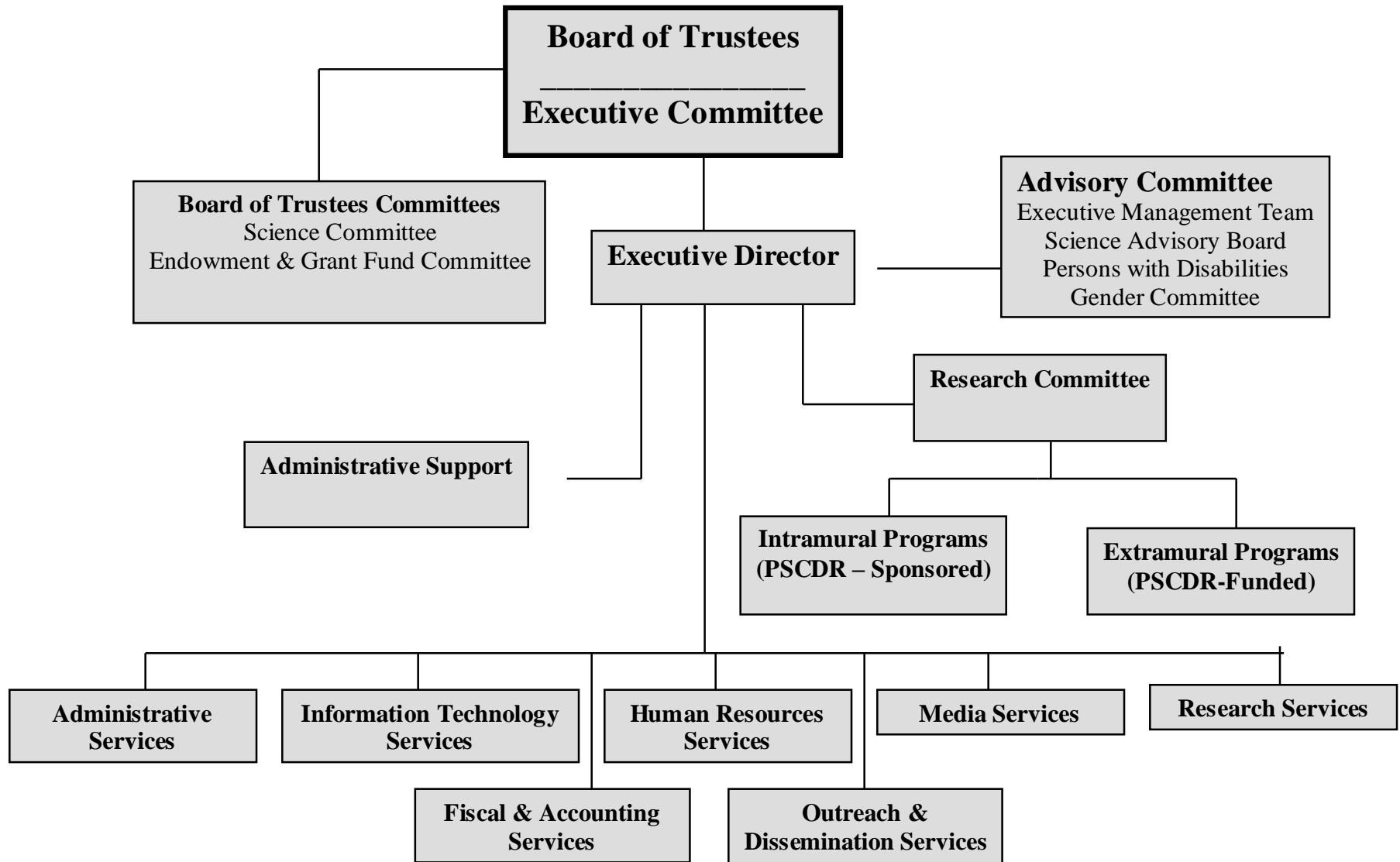
The Director's efforts are further facilitated by three other advisory committees. They are an international Science Advisory Board, a Persons with Disabilities Committee, and a Gender Committee. The Science Advisory Board is responsible for advising the Director with respect to the development and conduct of research programs at the Center. Appointments to this new international committee are just being made, and include (thus far) Dr. Joseph Piven, a professor of Psychiatry at the University of North Carolina, and Steven Warren, a professor of Speech and Hearing Sciences at the University of Kansas. Dr. Piven is also the Director of the Neurodevelopmental Disorders Research Center at the University of North Carolina and Dr. Warren is Director of the Kansas Research Center on Mental Retardation at the University of Kansas. The Persons with Disabilities Committee is made up of a group of individuals who advise the Director regarding all issues involving disabilities. Through their advice the Center has made significant progress in making the physical facilities of the Center more accessible to people with physical disabilities. Finally, the Gender Committee advises the Director regarding diversity in the personnel who work at the Center. During the past year approximately eight women have worked at the Center.

These committees, as well as the intramural and extramural research programs, and the core services that serve them, are depicted in the two organizational charts. That organizational framework was presented to the Board of Trustees at its meeting on June 6, 2001 (G).

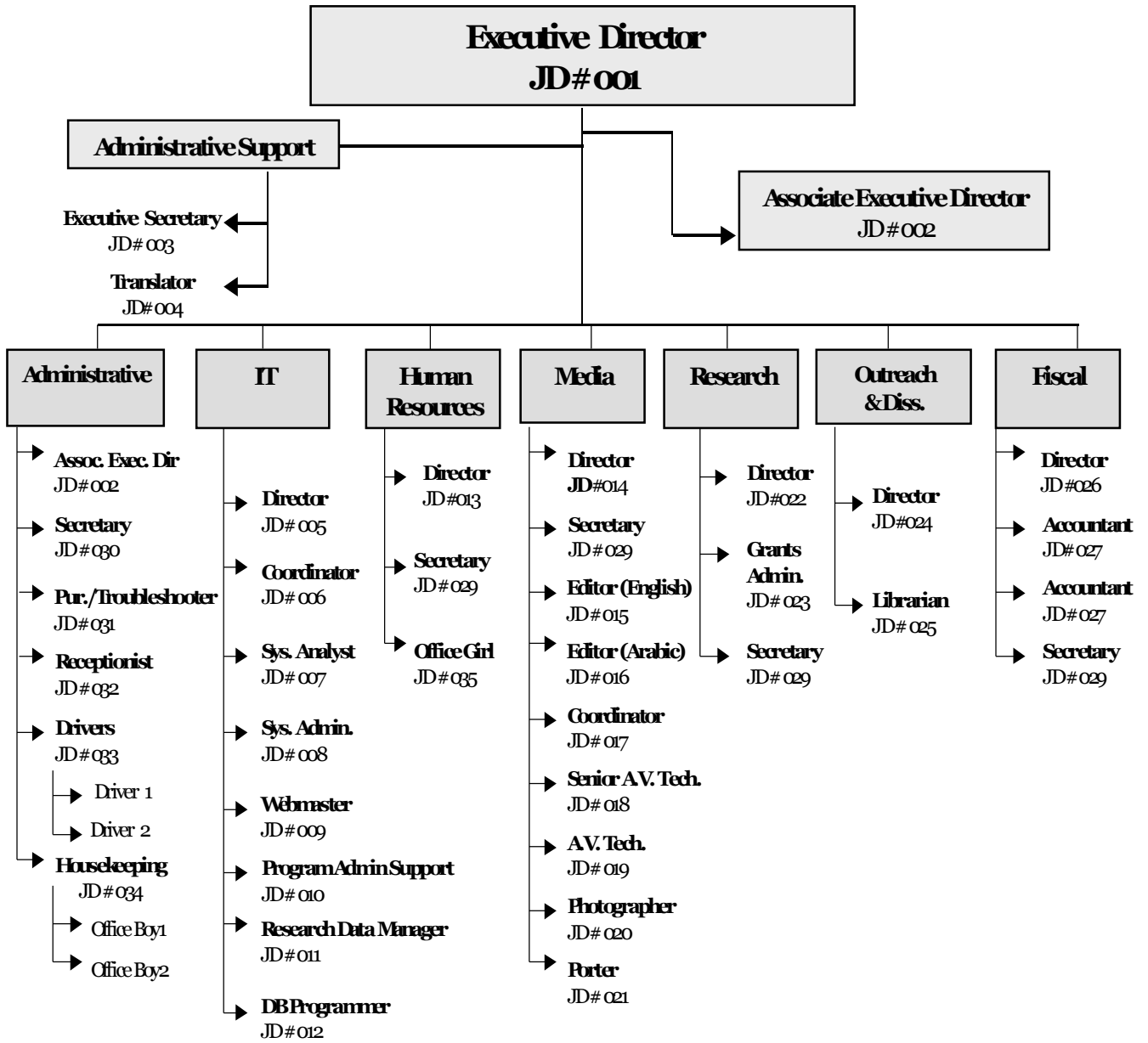
In the remaining sections of the report is described:

- Activities for each of the intramural research programs;
- Progress in the extramural research program;
- Activities and progress to date in each of the core services;
- Other accomplishments not previously cited;
- Anticipated activities in future years; and
- A proposed comprehensive budget, by objective and service, for the Year 2003 (G)

# PSCDR Organizational Chart



# PSCDR Organizational Chart- Core Services



## **II. RESEARCH PROGRAMS**

### **A. Intramural Research Programs**

The PSCDR has not conducted intramural research programs in the past. However, the new leadership of the Center proposed to the Board of Trustees at its meeting on June 6, 2001 (G) that intramural research programs be initiated. It was suggested that intramural research programs are essential to the long-term success of the PSCDR. That proposal was adopted and approved by the Board (Decision 1-24), and these programs are now being developed. Two of those, the “Genetics of Neurosensory and Neuromuscular Diseases” and “Language Development in Children,” are now being implemented. Both of these are high quality scientific programs, are relevant to the mission of the PSCDR, and have the potential to make important contributions to the health and well-being of the people of the Kingdom of Saudi Arabia. Efforts to develop a third scientific program, a “Newborn Screening Program,” are underway. The development of this program is more complex and will involve the collaboration of several institutions and ministries, as well as health facilities throughout the Kingdom. It has the potential to make a dramatic contribution to the identification and treatment of childhood diseases and disabilities in the Kingdom. Other proposed intramural research programs, enumerated below, are in earlier stages of planning.

#### **II.A.1. Genetics of Neurosensory and Neuromuscular Diseases**

##### **Goals and Objectives**

The overall goal of this research program is to characterize genetically hereditary neuro-sensory and neurodegenerative disorders prevalent in the Kingdom. The importance of the research is that it will lead to earlier diagnosis, development of new treatment strategies, genetic counseling for families, opportunities for pre-marital screening consultations, and a better understanding of the underlying molecular mechanisms of both rare Mendelian and possibly common polygenic neurological diseases.

A unifying feature of the disabilities being investigated is a failure of communication between the brain and another organ. This failure may be a consequence of altered brain activity or structure, an inability to detect external stimuli or to produce the correct nerve impulses, or defects in the organ tissue receiving the impulses from the brain. The initial efforts of this program will be to investigate five neurosensory and neuromuscular disorders with the aims of identifying the specific genes involved and mapping the regions of those genes that are responsible for these diseases. This initial work should be completed in three years.

##### **Background**

The underlying cause of many diseases is an alteration in the structure (DNA) of a single gene, a “mutation”, which manifests itself as a change in the confirmation, stability or expression of a resulting protein product. The mechanisms by which tissues or organs are altered as a result of this mutation are varied. The alterations can occur during the early stages of development or can be a result of cell/tissue degeneration over time. Changes in enzymes within metabolic pathways can result in the build up of intermediate compounds which can be toxic. Most genetic alterations manifest themselves only when both copies of the gene reflect the change, and these

traits are therefore regarded in genetic terms as recessive. Usually these altered genes are very rare within a population. However, within the Saudi population there is a higher than usual frequency of appearance of recessive traits. The first step towards the identification of the gene that underlies a particular disorder is linkage mapping. Linkage mapping identifies the region within the chromosome wherein the gene(s) responsible for the appearance of a given trait lies. The large family size prevalent in Saudi Arabia, often with multiple affected individuals, greatly facilitates linkage mapping without the need to recruit many families. Thus, this type of research, and the opportunity to identify and eventually treat these diseases is a unique opportunity in Saudi Arabia.

### **Progress to Date**

Myopathies are disorders such as muscular dystrophy in which the muscles develop progressive weakness and atrophy. Comparison of the different forms of myopathy has revealed considerable variability in the age at which the disease becomes apparent and in the muscle groups affected. To date, the gene responsible has been identified in only two of the myopathies. Newly-recruited PSCDR scientists (Hodgkinson, Bharucha) have identified a form of myopathy affecting the muscles of the lower limbs, characterized in biopsy (from a family in the southern region of the Kingdom) by the presence of rimmed vacuoles (see Bharucha, V.A., E.J. Cupler, S.A., Bohlega, C.E. Boumah, S.N. Abu-Amero, M. Kambouris, B.F. Meyer, C.A. Hodgkinson, "A Novel Distal Myopathy with Rimmed Vacuoles in a Large Saudi Kindred is Linked to Chromosome 12." American Journal of Human Genetics, Vol. 69, October, 2001). Bharucha et al. have mapped this disease to a small region of chromosome 12 covering approximately one Megabase of DNA. Two similar forms of this myopathy have been mapped elsewhere in the genome, demonstrating that this is a unique genetic and neurologic entity. Only two known genes lie within the identified region. One of these has been screened for the presence of mutations and has been excluded as a possible cause of the disease.

Hereditary Spastic Paraplegia (HSP) is another group of disorders in which the mode of inheritance, age of onset, and accompanying symptoms are variable. The common feature of this group of disorders is a progressive, generally severe, lower-extremity spasticity. HSP has been mapped to over 20 loci within the genome, but only a few genes have yet been identified. A single family from the northern part of the Kingdom has been identified that displays a novel form of HSP. Hodgkinson and Bharucha (see Hodgkinson, C.A., S.A. Bohlega, E.J. Cupler, SnN. Abu-Amero, C.E. Boumah, M. Kambouris, B.F. Meyer, V.A. Bharucha, "A Novel Autosomal Recessive Pure Hereditary Spastic Paraplegia in a Saudi Family Showing linkage to Chromosome 13q," American Journal of Human Genetics, Vol 69, October, 2001) have mapped the HSP to a 0cM region of chromosome 13, which covers approximately 2.2Megabase of DNA and includes 15 known genes. One of the genes (FLJ11712 ) within the region is related to two of the genes known to cause HSP. This was screened for mutations, and was excluded as the cause. Although no mutations were found in this gene, the data obtained has enabled us to further reduce the size of the region to be analyzed (see "A Novel Form of Autosomal Recessive Pure Hereditary Spastic Paraplegia Maps to Chromosome 13q14." C.A. Hodgkinson, S.A. Bohlega, E.J. Cupler, S.N. Abu-Amero, C.E. Boumah, M. Kambouris, B.F. Meyer, & V.A. Bharucha. In press Neurology, 2002 00:000-000).

A three year grant proposal for the analysis of HSP in the Kingdom has been accepted and blood samples from 3 families have already been collected, and it is anticipated that another 15 families

will be recruited. DNA for these families will be processed and analyzed as explained below (anticipated activities for the year 2003).

Deafness is another category of common, genetically-determined diseases prevalent in the Kingdom. Approximately 50% of all cases of deafness are due to alteration in a single gene. Genetic forms of hearing loss are classified according to whether the hearing loss appears alone or in association with other traits such as pigment abnormalities or mental retardation. Deafness has been mapped to over 80 loci and the genes responsible for several forms of hearing loss have been identified. For the majority of forms of genetic hearing loss, however, the genes remain unknown. The family studied for HSP (described above) also display congenital deafness, which is transmitted independently of the paraplegic trait. At the PSCDR, we have shown that the two disorders are not linked genetically. Preliminary data suggest that the deafness maps to chromosome 3 and also represents a new genetic form of deafness (see “A Refined Interval for the Autosomal Recessive Nonsyndromic Deafness Locus DFNB6”. C.A. Hodgkinson, S.A. Bohlega, E.J. Cupler, S.N. Abu-Amero, C.E. Boumah, M. Kambouris, B.F. Meyer, & V.A. Bharucha. American Society of Human Genetics Annual meeting October 2002).

### **Anticipated Activities in the Coming Year**

1. Selection of candidate genes for identification and mutation detection for the mapped HSP and myopathy disorders.

Candidate genes will be selected based upon sequence or functional similarity to known causative genes. Selected genes will be analyzed for the presence of mutations. Data obtained will be used to refine the region of interest and exclude and ultimately identify the causative genes.

2. Study of Genes Related to Deafness.

Families with hereditary deafness will be identified and classified according to the type of deafness (syndromic or non-syndromic) and the mode of inheritance. Linkage analysis will be performed using markers for known loci. Families that show no linkage to known loci will be analyzed further with the aim to map novel loci. In the case of both novel and known loci, attempts will be made to identify the gene underlying the deafness. Finally, mutations in known genes will be characterized.

3. Hereditary Spastic Paraplegia.

Cases of HSP in Saudi Arabia will be characterized according to mode of inheritance and clinical criteria. Specific marker panels will be developed for the analysis of loci known to link to HSP, allowing rapid genetic characterization of HSP within the Kingdom, and which will facilitate an analysis of locus versus phenotype and correlation of mutation to phenotype. Linkage of HSP to known loci will allow narrowing of the existing linkage intervals and to identification of the underlying gene(s). Novel genetic forms of HSP will be identified by exclusion of known loci, mapped to the smallest possible linkage interval and, where possible, the underlying gene(s) will be identified.

#### 4. Myopathies and Dystrophies.

Muscular dystrophies in the Kingdom will be classified by both clinical and genetic evaluation. Genetic classification will be performed by linkage studies using markers for known loci. This will allow an assessment of the geographical distribution of these disorders within the Kingdom, and allow the characterization of the mutations present in the Saudi population. In families that show no linkage to known loci, the novel loci will be mapped as a first step towards cloning the gene responsible.

#### **Personnel**

The scientists who comprise the research team conducting this research include:

Dr. Vandana Bharucha, PhD, Principle Investigator, will undertake the role as Principal investigator and will be responsible for the execution and management of the projects relating to neuromuscular and neurological defects. It is expected that 80 percent of her time will be allocated to these projects. Additionally she will be responsible for the preparation and submission of scientific manuscripts in peer reviewed journals and presentation of data at national and international conferences. (full-time).

Dr. Colin Hodgkinson, PhD, as Co-Principal investigator, will be responsible for carrying out the projects relating to deafness and ocular defects. It is expected that 80 percent of his time will be allocated to these projects. Additionally he will be responsible for the coordination with clinical co-investigators, and the preparation and submission of scientific manuscripts in peer reviewed journals and presentation of data at national and international conferences. (full-time).

Two technicians will be assigned to a given project and will be supervised by the project PI to assist in sample handling, DNA preparation, genotyping, and mutation detection techniques. (full-time/TBR).

#### **Collaborators**

This program is sponsored and administered by the PSCDR in collaboration with KFSHRC. KFSHRC provides 60 percent of the budget, as well as facilities and access to equipment along with necessary core services. In addition, there are many investigators at the KFSHRC who are collaborators on this project. They are:

Brian Meyer PhD. Head, Genomics Unit, Research Centre, KFSHRC, who will provide genotyping and sequencing services.

Marios Kambouris PhD. Head, DNA Diagnostics Laboratory, KFSHRC

Saeed Bohlega MD. Head, Section of Neurology, Dept. of Neurosciences, KFSHRC

Edward Cupler MD. Consultant, Dept. of Neurosciences KFSHRC, who will provide patient recruitment and diagnosis.

Khalid M. Taibah, FRCS. Head, Section of Otolaryngology & Communication Disorders, Dept of Otolaryngology, Head and Neck Surgery & Communication Disorders, KFSHRC, who will assist in patient recruitment and diagnosis.

#### **Budget**



## II.A.2. Language Development in Children

### Goals and Objectives

A preliminary examination of the type of communication disorder seen at the speech and language clinics in two major hospitals in Riyadh shows that approximately 45% of the pediatric population present with a diagnosis of delayed language. One of the great difficulties that face speech-language pathologists working in Saudi Arabia in particular, and in the Arab world in general, is the lack of appropriate assessment materials to use with children and adults. Most of the currently used assessment materials were designed for use with English-speaking American children. This makes them inappropriate linguistically, even though they are translated, because of the differences between Arabic and English in rate and pattern of acquisition. Moreover, such materials are not suited to Saudi children's experiences and often conflict with tradition and religion. This applies to testing as well as intervention procedures.

To date there are very few studies that have examined the normal development of speech and language in Arabic (i.e. normative data, or milestone development) and less than a hand full that have examined such issues in the Saudi community. This poses a significant problem in the diagnosis of audiological and speech-language deficits. In the absence of documented milestones and developmental guidelines, standardized tests cannot be developed. This lack of research and standardization renders clinicians incapable of making objective diagnoses, and may even prevent them from correctly diagnosing specific deficits.

One further problem that compounds the study of language development is the existence of several different Arabic dialects in Saudi Arabia. Unlike English dialects, dialects in Arabic not only differ in terms of phonemic pronunciation, but they differ in terms of phonology, morphology, and semantics. Variations across these major linguistic components make it essential to sample language across the major dialects spoken in order to acquire a comprehensive picture of development that is representative of the language spoken in the Kingdom as a whole.

The overall goal of this research program is to identify the developmental course of speech (phonemic and phonological) and language (morphological, syntactic and semantic) in children between the ages of 1 through 8 in the Kingdom.

The research has one primary and three secondary goals. The primary goal is to develop a national, normative database, a "gold standard," by which future assessment and diagnostic tests and tools can be developed and validated. The secondary goals are: (i) to develop an early identification tool that can be utilized in preschools, pediatrician offices, and speech-language clinics to help identify children who present with speech and language delays; (ii) to pilot test two computerized clinical applications for the analysis of language (one program will analyze phonemic and phonological subsystems and another will analyze morphological, semantic and syntactic subsystems) in *Arabic* that can be adapted and developed into clinical tools in the future (iii) to standardize a language comprehension assessment tool and; (iv) to collect information regarding the prevalence of speech and language disorders in the Kingdom of Saudi Arabia and the number of professionals working in the field.

## **Progress To Date**

During this past year the project has progressed on several fronts. These include: (i) funding, (ii) core team development, (iii) software development, (iv) data collection materials development, (v) increasing public awareness, and (vi) development of an Arabic phonetic alphabet.

Funding. Initial funding for the project was received on 6 March, 2002 G (22/12/1423H).

Core Team Development. Major efforts were made to develop a long-term core team that will support the progress of this project. During this year, two of the local consultants and the research assistant that were included as part of the team left the country and are no longer part of the research effort. Hence, an effort to involve local professionals has been made. The primary and co-investigators have continued to meet on a weekly basis. A linguist (M. Bakalla, Ph.D.) was identified and has agreed to serve as linguistic consultant. A consultant on the Arabization of the LIPP program (M. Amayreh, Ph.D./CCC-SLP) has joined the team. A logistics/data collector has been identified. In addition, an informal survey of professionals working in the field of speech-language pathology was conducted to identify key personnel to assist in the coordination and data collection on a national level. This survey yielded key personnel in both the Eastern province and Jeddah.

Software Development. Two software packages have been identified as the tools that will be used in the project. The *Logical International Phonetic Programs (LIPP)* and the *Systematic Analysis of Language Transcripts (SALT)*. These two packages have excellent potential for adaptation to the Arabic language. Preliminary efforts to identify Arabic structures that are of importance from a developmental perspective are underway. To date, phonological, syntactic and semantic structures have been identified.

Data Collection Materials Development. This area has shown the most progress in the past year. An initial pilot survey was conducted to determine the type of materials required for language sampling. This survey was limited to Riyadh after initial surveys indicated that most young children in this area do not use toys as a source of language stimulation. An initial list of culturally appropriate objects has been developed to help stimulate language sampling.

To test phonemic and phonological development, a list of words and a set of object and pictures have been developed. These words will be reviewed by a linguist for linguistic content after which they will be pilot tested in Riyadh over the first 6-months of the next year to determine the appropriateness of the material for the task.

To test receptive language abilities, a revision of a receptive language test developed by Dr. Alakeel was conducted. This included the addition of new test items and a complete revision of stimulus pictures that yielded a new picture manual.

Increasing Public Awareness. Due to the importance of public support for the proposed project several attempts at increasing public awareness to the importance of the information yielded by the results of this study were made. These included media coverage both in Arabic and English, lectures, and local and international presentations. These include:

October 2002 -Pediatric Review Course at Riyadh National Guard Hospital.

September 2002 -Pediatric Neurology Review Course at Riyadh Military Hospital. Two presentations.

April 2002 *Language development in Saudi children: What do we know?*

The Second Symposium on Speech and Language Disorders. University of Jordan, Amman, Jordan.

Development of an Arabic Phonetic Alphabet In collaboration with Dr. Mansour Alghamdi at the King Abdulaziz City for Science and Technology and the Speech and Language Development Team, have attended numerous meetings and development session on the creation and implementation of an Arabic Phonetic Alphabet. The development of this tool will enable right to left transcription of speech and language samples that will assist in the development of a computerized system that is purely based on the Arabic language.

#### Additional Activities at the Center:

In addition to the current project, the primary investigator of the project has been involved in a number of activities throughout the year at the center. These included:

1. Served as a member of the Extramural Research Committee.
2. Developing the Family Village and PSCDR web site.
3. Assisted in the organization of the “Best-Buddies” presentation.
4. Dissemination and Outreach.

#### **Anticipated Activities in the Coming Year**

The next year will include the pilot testing and comprehensive testing of all materials developed in the Riyadh area on a representative sample of children between the age of 1-8. Prior to the initiation of pilot testing, RAC approval from the King Faisal Specialist Hospital will be gained.

#### **Personnel**

The personnel required to conduct this research program are:

- Heidi A. Alaskary, PhD/CCC-SLP, Principal Investigator, a Speech Language Pathologist and academician, will be the Coordinator of the project and be responsible for research design and data collection (full-time).
- AbdulRahman Al-Akeel, PhD, SLP, a Speech Language Pathologist and academician, will be the Co-investigator and a participant in Research Design Group (part-time).
- Sadi Alzahrani, PhD/CCC-SLP, a Speech Language Pathologist, will be a Co-investigator and a participant in Research Design Group (part-time).
- Mohammad Bakalla, PhD. Will approve linguistic content of language sampling material for linguistic integrity and dialectal variations (part-time).
- Data collector. This individual will serve as national liaison with educational facilities and governmental institutions to facilitate data collection in schools (part-time/ TBR).
- Research Assistant, to co-ordinate and support activities of the project and provide secretarial assistance (full-time/ TBR).

#### **Budget**

**PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH**

**DETAILED BUDGET FOR YEAR 2003**

Proposed Duration of Project      From:      01/01/2003      To:      31/12/2003

**Department/Project:      LANGUAGE DEVELOPMENT PROGRAM**

**PERSONNEL**

<i>NAME</i>	<i>Months</i>	<i>% Efforts on Project</i>	<i>Annual Base Salary</i>	<i>Salary Requested</i>	<i>Total Benefits</i>	<i>Total Salary with Benefits</i>
PER ATTACHED			215,280	311,278	45,313	356,591

CONSULTANT'S COSTS

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EQUIPMENT COSTS						61,200
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SUPPLIES COSTS		Computer & Office Supplies				12,300
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		Tangible Reinforcement for Children(Sticker, Small Toys)				1,000
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		Library Books, Research Articles				58,400
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TRAVEL COSTS		ASHSA Conference 2002				39,250
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		2 Trips Dammam and 2 Trips Jeddah				2,080
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ALTERATION AND RENOVATIONS						0
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OTHER EXPENSES		SALT (Language Transcript Program) & Transcript Builder				2,276
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<b>TOTAL COSTS FOR 200 BUDGET</b>						<b>533,097</b>
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### **II.A.3 Newborn Screening Program**

#### **Goals and Objectives**

Based upon both published data, and anecdotal evidence from the King Faisal Specialist Hospital and Research Centre (KFSHRC) and other medical centers in the Kingdom, it is believed that Saudi Arabia has a high incidence of inherited metabolic and endocrine disorders. Many of these disorders carry serious clinical consequences for the affected infants, which include mental retardation, physical handicap, or death. Many of these diseases, however, are treatable with simple dietary measures or inexpensive medications provided they are rapidly and accurately diagnosed. Newborn screening of dry blood spots collected on filter paper is the most effective mechanism for early diagnosis.

Currently, there is nationwide newborn screening only for congenital hypothyroidism, and screening of a limited number of newborns for metabolic diseases at the Research Centre of KFSHRC, Riyadh. By 1999 (G) the hypothyroidism program had screened over 1,700,000 newborns and saved over 520 affected infants from mental retardation and physical disability. However, the fact remains that a very large number of metabolic and other endocrine cases are diagnosed every year at KFSHRC from sick or mentally retarded children where the window for effective treatment may have already closed. These cases cause a heavy financial burden on the health care system, as they require frequent hospitalization and intensive care. Many of these children also end up in disability centers around the Kingdom causing a major financial burden on social services. They also pose a heavy burden on the family both financially, and emotionally.

The overall goal of this program is to expand the current screening program for congenital hypothyroidism in the Kingdom into a major, national newborn screening program for metabolic and endocrine diseases. The specific objectives of the program will be to collect, in 2003 (G) dry blood spots from 75,000 newborns annually from different areas of the Kingdom, to screen these samples for 15 endocrine and metabolic disorders, to confirm identified cases, and to treat these infants at their own region in coordination with KFSHRC at Riyadh, or Jeddah. The number of samples will be increased to 150,000 in 2004 (G), and to all births in the Kingdom (approximately 400,000) in 2005 (G). This program will be sponsored and administered by the Prince Salman Center for Disability Research, in collaboration with KFSHRC. KFSHRC will provide existing facility and equipment, screening expertise, and test confirmation. In this regard, in July 2002 KFSHRC and Prince Salman Center for Disability Research signed a Memorandum of Agreement to collaborate and cooperate in expanding this technology to become a program of universal newborn screening for the entire Kingdom.

#### **Progress to Date**

For the past thirty years neonatal screening for metabolic diseases has been carried out largely using bacterial inhibition assays (BIA) of dry blood spots (DBS) collected on special filter paper as introduced by Dr. Robert Guthrie. These screening programs focused on a small number of diseases such as phenylketonuria (PKU) and maple syrup urine disease and involved one test for each disease. In 1994 the Metabolic Screening Laboratory (MSL) at the Research Centre of KFSHRC introduced tandem mass spectrometry (MS/MS) as an alternative, automated, high throughput, specific, and broad-spectrum approach to screening for over 20 metabolic disorders, including those covered by BIA tests. Since then, MSL has analyzed over 100,000 DBS samples

and has diagnosed over 2,000 metabolic cases, many of which are currently treated at KFSHRC or other hospitals. Other new technologies to be used are high throughput kit-based fluorometric assays available now for screening for hypothyroidism, biotinidase deficiency, congenital adrenal hyperplasia, and galactosemia from DBS samples.

It is not expected that this program will add a financial burden to the Kingdom. On the contrary, it is expected that the program will result in cost savings as the promptly treated cases will result in fewer hospitalizations and eventual institutionalizations, fewer clinic visits, and lower intensive care and medication costs than the current burden of dealing with severely affected patients.

During the year 2002 several fund-raising, cooperation-seeking activities and discussions took place. These included presentations and round-table discussions given to:

- HRH Prince Sultan Bin Salman Bin Abdulaziz.
- King Khalid Charity Foundation.
- HE Dr. Osama Shubukshi, Minister of Health.
- HE Dr. Saleh Al Azl, Director General, King Abdulaziz City for Science & Technology.
- HE Dr. Ketab Al Otaibi, Director, The Military Hospitals System Administration.
- HE Dr. Rashed Aba Al Khail, Director of Sultan Foundation.
- HE Mr. Abdul Aziz Al Shaikh, President of HRH Sultan Bin Fahd Bin Abdulaziz Office.

Discussion of collaboration between PSCDR, KFSHRC, and the Ministry of Health. These discussions involved representatives from Ministry of Health, Ministry of Finance, and Ministry of Planning based on a directive issued by HRH Prince Abdulaziz Bin Fahd Bin Abdulaziz.

### **Anticipated Activities in the Coming Year**

It is anticipated that initial efforts will involve:

1. Additional fund-raising activities.
2. Signing a Memorandum of Agreement between different interested parties to push forward the start of the program.
3. Four regions will be selected: Riyadh, Jeddah, Qassim, and Abha. It is estimated that we can easily acquire 75,000 newborn samples during the year from these four regions. The target hospitals are maternity and children hospital.
4. Information booklets will be distributed to each hospital that will include appropriate methods of blood spot collection, information requested on the card, how to communicate with MSL, diseases screened, and other information.
5. A coordinator will be selected in each participating hospital to coordinate the collection of samples, shipment of samples to MSL in Riyadh, recall of patients for repeat analysis, receiving feedback from the screening facility, providing test results to physicians and families.
6. A coordinator will be assigned at KFSHRC to work with the regional coordinators towards the smooth transition of samples from the regions to the lab, requesting repeat samples, sort out any communication difficulties, coordinate consultation between regional physicians and KFSHRC consultants.

7. The screening facility will be the Metabolic Screening Laboratory existing at the Research Centre of KFSHRC, Riyadh. The facility currently has the backbone for the project in terms of expertise, equipment, supplies for the MSMS assays, and for confirmation tests.
8. The results of the screens will be entered into a recording system and any abnormal results will be reported by fax, and conveyed by telephone by the KFSHRC coordinator to the regional coordinators.
9. A report will be issued for every newborn tested to go into his medical file at the regional hospital. This report will indicate the diseases tested for and indicate test results.

## **Brief Description of the Diseases included in the Screening Plan**

### **1. Phenylketonuria (PKU)**

Brief Clinical Description: PKU is an autosomal recessive disorder caused by deficiency of phenylalanine. Incidence 1:10000 to 1:25000 in United States, but not yet documented in the Kingdom of Saudi Arabia Clinical outcome without Diagnosis and treatment: progressive developmental delay, severe mental retardation, seizures, autistic like behavior. Clinical outcome with screening and treatment: Normal early growth, development and normal range of intelligence with optimal dietary control.

### **2. Maple Syrup Urine Disease (MSUD)**

Brief clinical description. MSUD is an autosomal recessive disorder. Incidence: US mixed population 1: 300,000, highest in Mennonite population (1 in 760); not documented in Saudi Arabia. Clinical outcome without Diagnosis and treatment: Classical form (most common in Saudi Arabia) is lethal in the first month of life if unrecognized, and untreated. Other forms cause significant morbidity. Clinical outcome with screening and treatment: may prevent death caused by the classical form in some cases but not all (based on international experience). Better neurological outcome if detected early before the classic neonatal crisis.

### **3 & 4 Urea Cycle Defects Argininosuccinic acid synthetase deficiency (citrullinemia-ASD) and Arginin succinic acid lyase deficiency (ASL)**

Brief Clinical Description. ASD and ASL belong to the group of urea cycle disorder. Incidence: exact incidence unknown; it appears to be quite common in Saudi Arabia. Clinical outcome without Diagnosis and Treatment: Clinical severity varies with early onset severe cases to late onset milder variants. Without treatment early onset forms are usually lethal. Late onset and milder forms can result in significant morbidity and sometimes mortality if not detected early. Clinical outcome with screening and treatment: Not all neonatal crises can be presented by Newborn screening (International data). However if treated before crisis, the overall outcome is improved.

### **5. HMG–CoA lyase deficiency (HMG)**

Brief clinical description. HMG is a branched chain organic aciduria. Incidence: Unknown – many cases are detected yearly in Saudi Arabia. Clinical outcome without diagnosis and treatment: One third of the patients present in the neonatal period and two thirds present

between 3 and 11 months of age, with severe hypoglycemia, metabolic acidosis, and hyperammonemia. Clinical out-come with diagnosis and treatment: Most patients do well.

#### **6. Isovaleric academia (IVA)**

Brief clinical description. IVA is a branched chain organic aciduria. Incidence: unknown; detected every now and then in Saudi Arabia. Clinical outcome without diagnosis and treatment: The disease may present in the neonatal period with severe metabolic acidosis and vomiting which may lead to coma and death. Clinical outcome with screening and treatment: Screening may fail to prevent neonatal crisis in some patients. Death and severe neurological sequelae would be avoided in those escaping early neonatal crisis and long term neurological out come is favorable.

#### **7. Methylmalonic acidemia (MMA)**

Brief clinical description. MMA is a group of defects associated with a break down of organic acids. Incidence: Combined frequency 1 in 50,000. MMA is one of the most common organic acidurias in Saudi Arabia. Clinical outcome without diagnosis and treatment: Presents with neonatal or infantile metabolic ketoacidosis that may proceed rapidly to coma and death if untreated. Clinical outcome with screening and treatment: Death or neurological damage may be prevented with diagnosis and treatment before neonatal crisis. Overall outcome is variable.

#### **8. Propionic academia (PA)**

Brief clinical description. PA is an autosomal recessive disorder. Incidence: 1 in 500,000 in the U.S.A.; one of the most common organic acidurias in Saudi Arabia. Clinical outcome with out diagnosis and treatment: Presents within few days of life with poor feeding, vomiting, metabolic acidosis and coma which may proceed rapidly to hyperammonemia and death if untreated. Clinical outcome with diagnosis and treatment: Death may be prevented with diagnosis and treatment before neonatal crisis. However neonatal crisis may not be prevented in all cases.

#### **9. Beta-Ketothiolase Deficiency (BKT)**

Brief clinical description. BKT is an autosomal recessive disease. Incidence: Unknown. Clinical outcome without diagnosis and treatment: quite variable. Some patients may have developmental retardation. Clinical outcome with screening and treatment: Very good. Patients experience less metabolic crisis and their mental development appears to be normal.

#### **10. Glutaric Acidemia type-1 (GA-1)**

Brief clinical description. GA-1 is an autosomal recessive disorder. Incidence: General frequency 1 in 30,000 in the U.S.; many cases are detected in Saudi Arabia each year. Clinical outcome without diagnosis and treatment: after the initial onset, the neurological course is gradually progressive with episodes of acidosis, vomiting, seizures and coma. Clinical outcome with screening and treatment: Quite variable, however, current data suggests that early intervention slows or halts the progression of neurological course. Most patients continue with some neurological impairment.

#### **11. Medium-chain acyl-CoA dehydrogenase (MCAD)**

Brief clinical description. MCAD is an autosomal recessive condition. Incidence: One of the most common fatty acid oxidation defects in the west; not documented in Saudi Arabia. Clinical outcome without diagnosis and treatment: Metabolic crisis is triggered by fasting or infection

and is characterized by nonketotic hypoglycemia which can cause death. Clinical outcome with screening and treatment: Very good. Episodes of metabolic crisis are prevented or at least reduced. Long-term neurological development is better with early diagnosis and treatment.

## **12. Galactosemia**

Brief clinical description. An autosomal recessive disorder. Incidence: 1 in 70,000 for classic Galactosemia. Several cases detected each year in Saudi Arabia. Clinical outcome without diagnosis and treatment: Classical galactosemia is fatal. Clinical outcome with screening and treatment. Death is avoided in most cases. Developmental outcome is variable but data suggests that early treatment is associated with better results. Some learning disabilities continue in spite of therapy.

## **13. Biotinidase deficiency**

Brief clinical description. Biotinidase deficiency is an autosomal recessive disorder. Incidence: 1 in 72,000 to 1 in 126,000 in the United States; not documented in Saudi Arabia. Clinical outcome without diagnosis and treatment: Death may occur during metabolic crisis. Developmental disabilities are inevitable without treatment and include convulsions, ataxia, hypotonia, developmental delay, hearing loss, optic atrophy, and or decreased vision. Clinical outcome with screening and treatment: Very good. Early screening and treatment are associated with normal development.

## **14. Congenital Hypothyroidism (CH)**

Brief clinical description. Congenital hypothyroidism represents one of the most common preventable causes of mental retardation. Incidence: in Saudi Arabia it is the same as worldwide, about 1:4000. If we assume that the birth rate in Riyadh area only is 70,000 newborns per year, so the total number of newborns with congenital hypothyroidism is approximately 18 per year. Clinical outcome if left undetected and untreated: newborns with congenital hypothyroidism who are undiagnosed will definitely develop varying degrees of mental retardation. Clinical outcome if detected and treated: it appears that early detection and treatment of congenital hypothyroidism should have the potential to completely reverse adverse health effects. Since the development of pilot screening programs for congenital hypothyroidism in Quebec and Pittsburgh in 1974 newborn screening for congenital hypothyroidism has become routine in essentially all developed countries of the world and is under development in Eastern Europe, South America, Asia, and Africa. In North America it is estimated that more than 5 million newborns are screened, with approximately 1400 infants with congenital hypothyroidism detected annually. The screening programs have benefited patients and their families and produced new information regarding the epidemiology, pathophysiology, diagnosis, and treatment of thyroid disease in infancy and childhood. The cost effectiveness: Congenital hypothyroidism is one of the most common preventable causes of mental retardation. The cost of health care of a mentally retarded child in Saudi Arabia is approximately 100,000 SR per year, 50 SR per newborn.

## **15. Congenital Adrenal Hyperplasia (CAH)**

Brief clinical description. Congenital adrenal hyperplasia consists of a family of enzymatic disorders. Incidence: the disorder occurs in 1 of 21 000 newborns in Japan, 1 of 10 000 to 16 000 in Europe and North America, and 1 of 300 in Yupik Eskimos of Alaska. However, it is 1 in

5000 in Saudi Arabia. Clinical outcome if left undetected and untreated: depending upon severity and type, patients may die during the newborn period of shock resulting from salt wasting. Clinical outcome if detected and treated: the major objectives of newborn screening for CAH attributable to 21-OH deficiency are to identify infants at risk for the development of life-threatening adrenal crisis and a range of adverse conditions.

### **Personnel**

- Mohammed Rashed, PhD, Director of the MSL and will be principal investigator of the program, (full-time).
- Mohamed Al-Amoudi, BSc, Supervisor of MSL, oversees technical programs (full-time).
- Minnie Jacob, MSc, Assistant technician, responsible for screening activities (full-time).
- Lujane Al-Ahaideb, BSc, Assistant technician, assists in screening activities (full-time).
- Vi-Sharon Legaspi, BSc, Assistant technician, assists in screening activities (full-time).
- Maria Elena Bernable , BSc, Data clerk, enters demographic and patient data (full-time).
- Program Coordinator, RN, Coordinator, oversees patient care activities (full-time/TBR).
- Senior Technologist (western trained), (full-time/ TBR).
- Junior Technologist, (full-time/ TBR).
- Junior Technologist, (full-time/ TBR).
- Junior Technologist, (full-time/ TBR).
- Data Entry Clerk, (full-time/ TBR).
- Data Entry Clerk, (full-time/ TBR).
- Secretary, (full-time/ TBR).

### **Budget**

**PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH**

**DETAILED BUDGET FOR YEAR 2003**

Proposed Duration of Project From: 01/01/2003 To: 31/12/2003

**Department/Project: NEWBORN SCREENING PROGRAM**

**PERSONNEL**

<i>NAME</i>	<i>Months</i>	<i>% Efforts on Project</i>	<i>Annual Base Salary</i>	<i>Salary Requested</i>	<i>Total Benefits</i>	<i>Total Salary with Benefits</i>
PER ATTACHED			1,575,972	1,575,972	725,826	<b>2,301,798</b>

CONSULTANT'S COSTS 0

EQUIPMENT COSTS **1,488,000**

SUPPLIES COSTS **2,335,000**

TRAVEL COSTS **100,000**

ALTERATION AND RENOVATIONS 0

OTHER EXPENSES **10,000**

Existing Equipment Maintenance **500,000**

**TOTAL COSTS FOR 2003 BUDGET **6,734,798****

#### **II.A.4. Research Programs in Early Planning Stages**

Other intramural research programs are currently under review and development. They include the following:

##### **Genetics, Neurobiology, and Neuropsychology of Autism**

Autism is a developmental disorder with one of the fastest rising incidence rates in the world. Although there is not sufficient documentation, the incidence of autism is purportedly increasing rapidly in the Kingdom. It is a difficult disease on which to collect secondary data because of the wide range of strategies employed in diagnosis, treatment, and reporting. In collaboration with scientists at several institutions in Riyadh, the PSCDR is assembling a research team that involves pediatricians, psychologists, geneticists, electrophysiologists, and brain-imaging scientists to study autism. The initial projects will include examination of several loci in the genome reported to be associated with autism, and other efforts to more definitively characterize the phenotype of autistic children. Autism is a high priority internationally and PSCDR aspires to become a member of this International Research Network.

##### **Epidemiology of Childhood Disabilities in Kingdom**

As noted above, although there is currently conflicting information about the incidence of various diseases and disabilities in the Kingdom, there have been few efforts to document either the incidence or the nature of these diseases. Further, with few exceptions, little information has been gained about their geographical or familial distribution in the Kingdom. Exceptions include some research on blood diseases, deafness, cancer, diabetes, and new research on neural tube defects. The PSCDR, in collaboration with scientists at KFSHRC, and epidemiologists in England and in the United States, is planning a national, comprehensive epidemiological study of developmental disabilities in a typical rural village in the Kingdom.

##### **Policy Research and Advocacy**

As various governing and legislative bodies address issues related to the needs of persons with disabilities, there is often a dearth of relevant information upon which to base policy. The PSCDR is planning the development of a policy research program which will consist of experts in various fields of disabilities working with policy analysts and researchers. These individuals will address a wide range of policy issues related to disabilities, including the need for a national early intervention system, the advisability of new competitive employment programs for persons with disabilities, the need for modified and expanded educational and health care systems for persons with disabilities, the need for changes in the standards and characteristics of communication and information technology systems in order to enhance their accessibility by persons with disabilities, and other issues.

##### **Research on Premarital Screening Programs**

Much research, both here in the Kingdom and internationally, is contributing new knowledge about the underlying genetic causes of inborn errors, birth defects, and a myriad of profound childhood diseases and disorders. This new knowledge, properly assembled and applied, could

be used to ascertain the risk of these diseases by screening blood samples of a couple considering marriage. Such information could be made available to individuals in premarital screening clinics.

## **II.B. Extramural Programs**

### **II.B.1. Overview of Past Activities**

The extramural support of research projects, provided in response to applications from investigators in the Kingdom, has been the primary activity of PSCDR. Since 1993 approximately 12 projects have been funded by the Center. Of those 12, three are active projects being supported at the present time and are nearing to completion. In addition, there are six newly funded projects.

### **II.B.2. Ongoing Projects Currently Being Funded**

#### **Project One**

Research Title “ Psychometric Scale for the Assessment of Behavioral Problems in Children in the Kingdom of Saudi Arabia”

Principal Investigator Prof. Saeed bin Abdullah Dubais

Co-investigators. Dr. Alsayed Al Samadoni and Azzah Omar Al-Ghamdi

#### Goals of the Research

The goal of this project is to modify the Finland Scale for the assessment of adaptive behavior for use in Saudi Arabia. Specifically, the project intends to translate the scale and to standardize its uses in an Arabic environment. Financial and narrative progress reports on this project have been unsatisfactory. Unless the investigators become more accountable on this project, it may have to be terminated.

#### Progress to Date

According to the indication of the principal researcher in the first technical and financial report, the following scales have already been modified and standardized in Arabic:

1. The teacher’s scale for the behavior of the disabled child
2. The parents’ scale for the behavior of their disabled child
3. The scale of the disabled student for his behavioral problems that are related to the school environment
4. The scale of the disabled student for his behavioral problems that are related to his relationships with his friends
5. The social distance scale

#### **Project Two**

Research Title “Stroke in Saudi children, Clinical Features, Etiology, Risk Factors & Prognosis”

Principal Investigator Prof. Mustafa bin Abdullah Mohammad Saleh

Co-investigators Prof. Abduljalil Mohammad Abdulquader, Prof. Hasan Bahakeem Mohammad, Dr. Mohammad Nasser Al-Nasser, Dr. Saleh Al-Mufadda, and Dr. Ahmad Ali Aljarallah

### Goals of the Research

This study intends to describe the nature of, and correlative factors associated with, strokes that occur in young children in the Kingdom. The study will also evaluate the results of various treatment strategies. It is expected that the results of the study will contribute to the development of new and standard treatment strategies as well as new preventive strategies.

### Progress to Date

1. Phase one: Data and literature search for the theoretical foundations of the proposed research have been completed.
  - a. relevant hard copies of articles both within and outside the Kingdom.
  - b. relevant updating of textbooks which are related to some of the important causes of childhood stroke.
2. Phase two:
  - a. based on the pertinent information in the research project proposal and the accumulating updating data and literature, a comprehensive protocol for retrospective data retrieval was designed; flexibility has been maintained in protocol to suit the prospectively recruited cases.
  - b. New cases of childhood stroke were recruited and followed during this period.
4. Phase three:
  - a. This project has shown excellent progress. It will finish on February 1, 2003. The investigators are now performing statistical analyses. A published report is anticipated by March 1, 2003.

### **Project Three**

Research Title “Clinical Epidemiological Study of Stroke-related Disabilities & Associated Risk Factors”

Principal Investigator Prof. Abdulrahman bin Yousif Al-Tahan

Co-investigators Dr. Sulaiman bin Abdullah Al-Shammari, Dr. Talaat bin Hamzah Al-Waznah, Prof. Saad Al-Rajeh, and Dr. Faek Al-Khoziki

### Goals of the Research

The risk factors associated with stroke in the Kingdom of Saudi Arabia have been studied previously, but none of these studies evaluated the factors that contribute to the subsequent chronic disability often associated with strokes. This research project will examine several aspects of strokes in children and factors associated with their recovery. Specific aims include:

1. describing the results of the stroke during the first year to define the magnitude of the disability caused by the stroke;
2. defining the kind and severity of the disability caused by the stroke;

3. defining the risk factors associated with the occurrence of the disability caused by the stroke;
4. examining the style of life for the disabled after the stroke: psychologically, physically and socially;
5. studying the kind of services extended to patients in their homes or in the hospital, including evaluation of support extended to the patient by his/her family.

#### Progress to Date

The project has just been initiated. It was delayed for 12 months due to a delay in approval of the Human subjects protocol and to difficulty in winning cooperation from referring hospitals. These problems have now been solved, and the project is underway.

#### **Project Four**

Research Title “The Rights of the Handicapped in Islam”

Principal Investigator Mohamed Mostafa Mohamed Ghaly

#### Goals of the Research

The goals of this project are to examine the rights of the handicapped in Islamic theology and Islamic *fiqh*, in order to understand the needs of and the provisions for people with handicaps in the norms of religion. Their financial and non-financial rights will be explored both as members of their family and in society.

#### Progress to Date

This study has just begun.

#### **Project Five**

Research Title “Preimplantation Genetic Diagnosis for the Prevention of Genetic Diseases”

Principal Investigator Dr. Ali Al Hellani

Co-Investigators Dr. Serdar Coskun, Dr. Ali Al-Odaib, Dr.Kernal Jaroudi, Dr. Pinar Ozand, Dr. Nadia Sakati, Dr, Aida Al-Aqeel

#### Goals of the Research

This proposal is to study genetic mutations in a group of devastating autosomal recessive diseases that occur with higher than usual frequency in the Saudi population. The results will be used to implement preimplantation diagnosis and in vitro fertilization with an embryo identified as free of the mutation studied, in order to produce a healthy baby.

#### Progress to Date

This study has just begun.

## **Project Six**

Research Title “The Effect of Early Detection and Prompt Treatment on the Disability and Mortality Caused by a Common Fatty Acid Oxidation Effect”

Principal Investigator Dr. Mohamed Rashed

Co-Investigators Dr. Zuhair Rahbeeni, Dr. Moeen Al-Sayed, Dr. Ali Al-Odaib

### Goals of the Research

In this study, the specificity of tandem mass spectrometry will be examined by a technique developed by the Principal Investigator for early detection of metabolic disorders, using a single drop of blood from newborns from the Northern Region who have a high incidence of a serious birth defect involving very long chain fatty acid oxidation. The investigators will also examine the effect of early medical intervention with or without carnitine on preventing the handicaps related to this defect. The cost-effectiveness of this newborn screening will also be examined.

### Progress to date

This study has just begun.

## **Project Seven**

Research Title “ Neural Tube Defects in Saudi Arabia: Incidence, Degree of Disability and Risk Factors”

Principal Investigator Dr. Waleed R. Murshid

Co-Investigators Dr. M.A.M. Salih and Dr. J.S. Jarallah

### Goals of the Research

Neural tube defects are a common cause of disability that occur during the embryonic period of pregnancy. Their effects involve multiple systems of the body. Cost of care and treatment are very high. The aims of this study are to estimate the incidence of neural tube defects and the degree of disability in a cohort of the Saudi population. It will also detect any preventable risk factors. The results will help in future planning for the reduction of this major handicapping illness in Saudi Arabia.

### Progress to Date

This project has just begun.

## **Project Eight**

Research Title “Universal Newborn Screening for Saudi Infants”

Principal Investigator Dr. Ziad Rafii

Co-Investigators Dr. Safaa Al-Essa, Dr. Muafak Diab, Dr. Haifa Al-Hajjaj

### Goals of the Research

Identification of hearing loss before six months, followed by appropriate intervention, is the most effective strategy for the normal development of language in infants and toddlers with hearing loss. The incidence of hearing loss in Saudi infants is not known, although the prevalence among adults is very high. This study, which will be conducted at three sites in Riyadh, is designed to detect the incidence of hearing loss in infants.

### Progress to Date

This project has just begun.

### **Project Nine**

Research Title “Design and Implementation of a Computerized Arabic Braille Environment”

Principle Investigator Dr. AbdulMalik S. A. Al-Salman

Co-Investigator Hend Suliman Al-Kalifa

### **Goals of the Research**

People with visual disabilities in the Middle East have many difficulties and barriers when using computers. The proposed Computerized Braille Environment will enable computer users with visual impairment to enter their data and information using any personal computer with no need for special equipment. With this procedure in hand, they will be able to communicate with the outside world without a need for a third party to handle the process of translating or dictating.

### Progress to Date

This project has just begun.

### **II.B.3. New Extramural Grant Program Processes and Procedures**

One of the limitations of the previous PSCDR extramural grant program was the time-consuming process by which applications were reviewed, funding recommendations made, and eventual support provided. Of the projects for which support was initiated this year, all were associated with research applications submitted to the PSCDR for review two to three years ago. One of the primary causes for delay was the fact that funding was not provided directly by the PSCDR. Support was sought from an outside benefactor after the decision was made to award a grant. As a result of these delays, it is conjectured that many of the researchers in the Kingdom capable of conducting high quality and significant research have not submitted applications to the Center.

To rectify earlier procedural limitations, and to elicit the participation of productive researchers to the programs of the PSCDR, the Center has been involved in the development of new administrative and review processes and procedures. These processes and procedures will represent a timely and effective review and funding-decision process culminating in an immediate grant award. In addition, as a result of a proposal submitted to the Board of Trustees at the June 6, 2001 meeting, the Board approved (Decision 1-24) an allocation of five million (5,000,000) SR to the support of extramural research. The cumulative effect of all these efforts is

that the Center is now capable of receiving, reviewing and funding research applications in a matter of six-to-eight months. We expect increased participation in the Center's extramural research programs as these new procedures take effect and the science community becomes aware of them.

Among the changes recently instituted at the PSCDR is a new, web-based process by which all forms needed to submit an application can be accessed on a new Center web page. In addition, the applicant can prepare and submit the entire application via the Internet. These changes can be viewed at <http://www.pscdr.org.sa/grantapplication.html/>. The review processes employed by the Center are also being modified to enhance their effectiveness and timeliness. One of those modifications, as described to the Board of Trustees at the June 6, 2001 meeting, is to change the makeup and role of the Research Committee, the group that reviews applications. As proposed at that time, the Committee will function more as a Study Section in which all applications and reviews of applications will be discussed and integrated by the processes of the Committee. In addition, the Center is planning to enhance the use of ad hoc peer reviewers from throughout and outside the Kingdom. Those reviewers will be provided with a copy (electronic) of the application and a set of specific instructions delineating the dimensions of the expected review. The end result of the Research Committee's procedures will be a list of funding recommendations, ranked on absolute and relative scales. Those recommendations will then be reviewed and submitted for approval to the Science Committee of the Board of Trustees. At the conclusion of these processes grant awards will be negotiated with the respective principal investigators and appropriate media and public announcements prepared.

A flow chart depicting these procedures is attached as a summary of these review procedures. This information will also be presented to individuals who submit research applications.

The Center conducts an extramural Research Grant Application competition on a semiannual basis. The same research priorities will be addressed for the two competitions within a given calendar year. The first two of those semiannual competitions were very successful. Investigators submitted 25 proposals. Over 100 scientists from throughout the world reviewed them. Six projects were funded. The next deadline for applications was October 15. Currently five research applications are under review.

#### **II.B.4. Research Priorities**

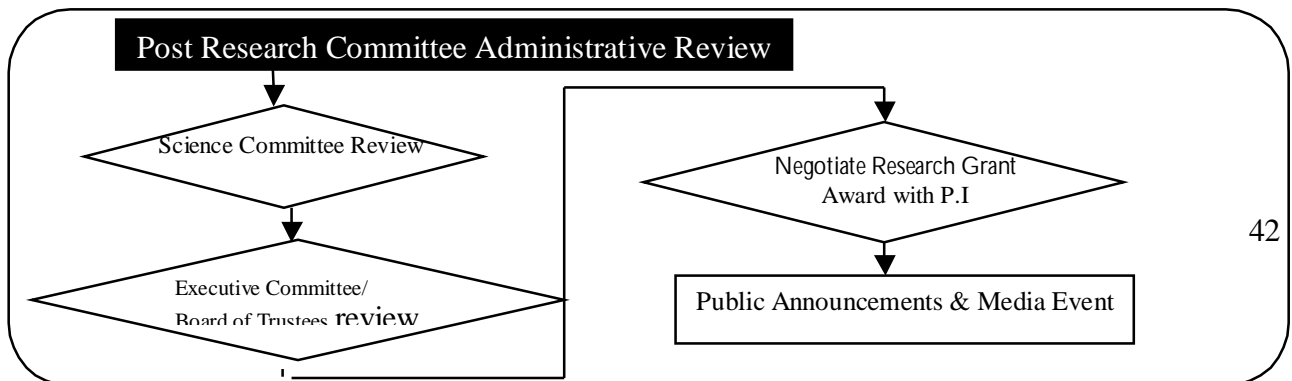
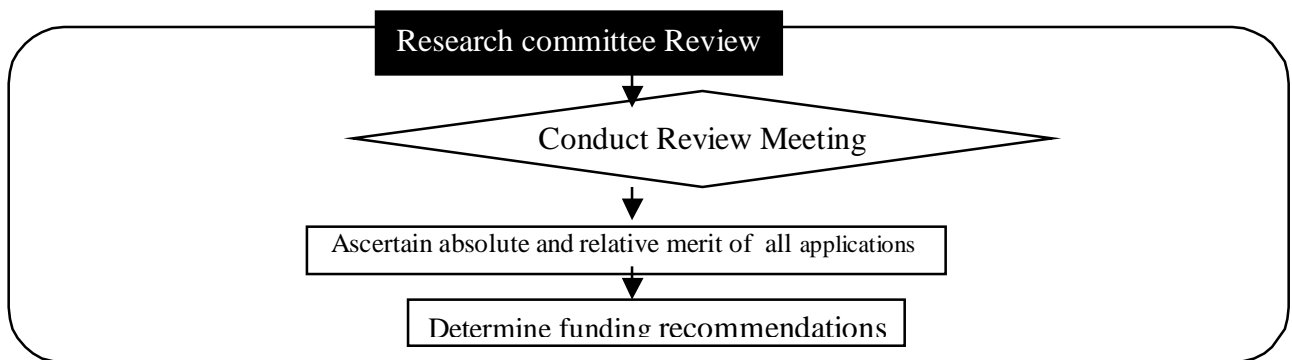
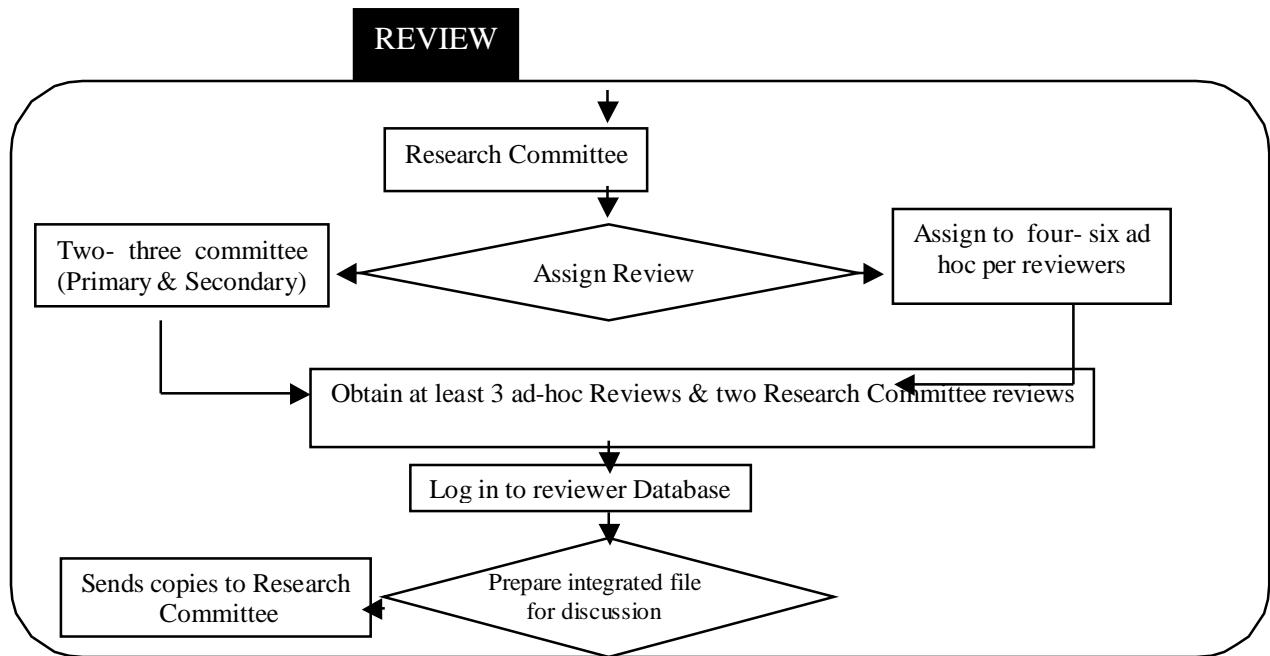
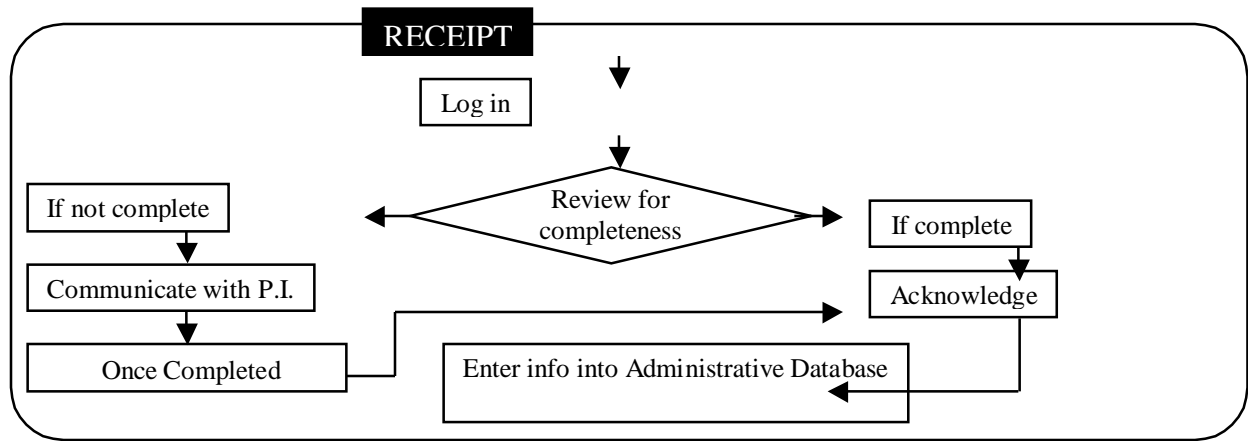
For the current year we are retaining the same research priorities as announced last year. (The Seventh Annual Research Program, 1422 H, 2001 G). The ten are:

- 1. The role of Islamic Shariaah in the service and support of persons with disabilities.**
- 2. Screening, early identification and management of common genetic diseases.**
- 3. Epidemiology of childhood disabilities (congenital and acquired).**
- 4. Development of diagnostic screening assessment and intervention tools [including cognitive development, speech and language development, and other developmental indices (projects on a Unified Arabic Sign Language also accepted)].**

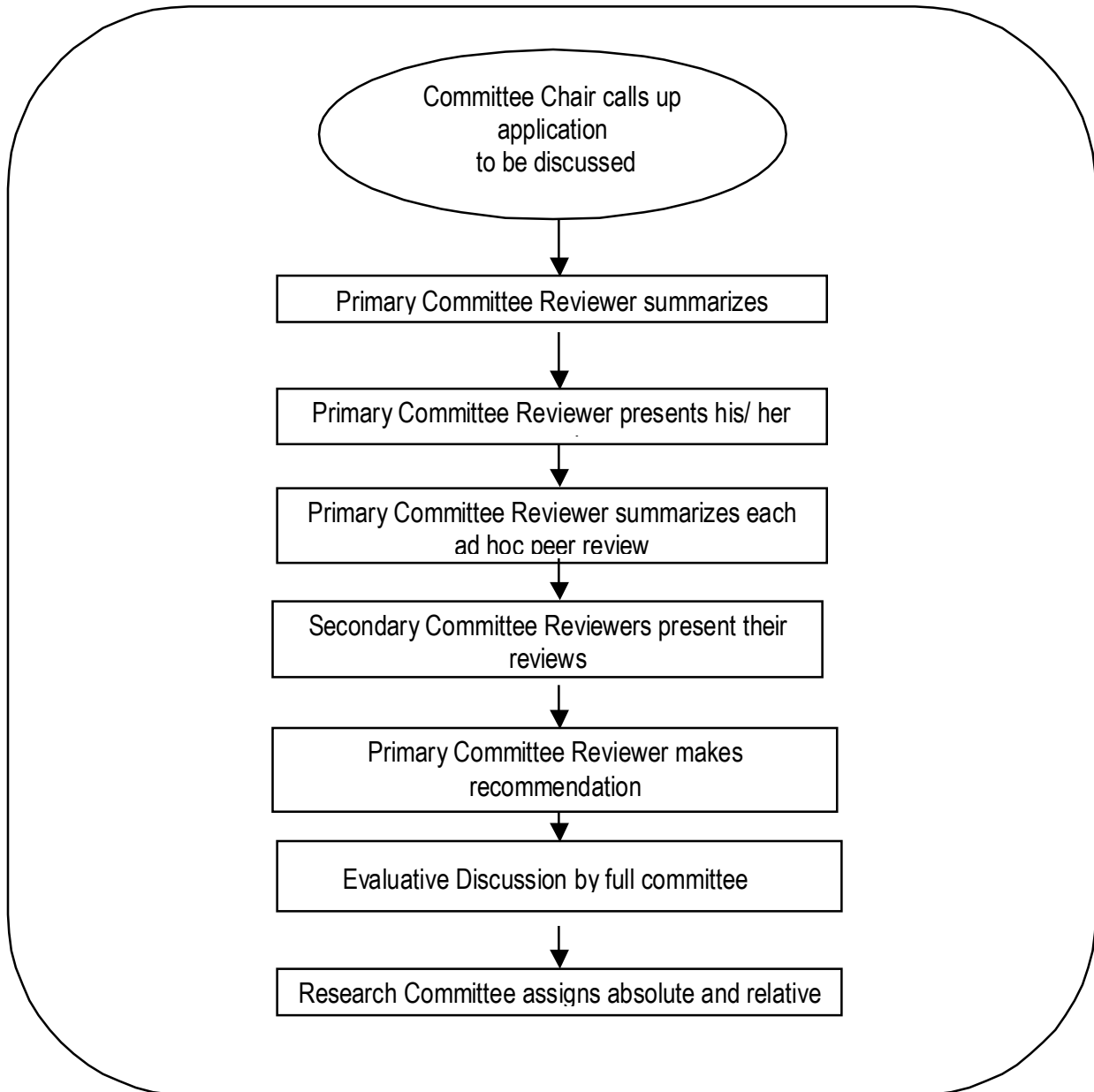
- 5. Research on diagnosis and intervention of Autism, ADHD, and related behavioral syndromes in children and young adults.**
- 6. Research on early intervention programs (0-3 years) for children with or at risk for disability.**
- 7. Use of computers and assistive technologies to improve quality of life for persons with disabilities.**
- 8. Policy research related to the needs for service and support for persons with disabilities and their families.**
- 9. Role of persons with disabilities, their families, and community organizations in service and support to persons with disabilities.**
- 10. Evaluation of fiscal and economic issues in research on disabilities.**

These ten priorities were announced using a variety of media, including the Internet, personal mailings, the distribution of several thousand posters, and announcements at meetings. Permission also was granted to submit research applications on other topics not among the ten priorities. Also, support is planned for students who are preparing dissertations and comparable documents.

## Processing of Research Grant Application



## Research committee Review



### **III. Other Accomplishments During 2002 (G)**

In addition to the activities already described, other accomplishments during the past year include the following:

#### **III.A. Recruitment and Termination of Personnel**

Seven new employees were recruited in 2002 after intense screening of over 700 applicants. Among them were an Accountant, Grant Administrator, a Librarian, our Manager of Information Technology, and our Media Director. These are key recruits who will shape the future of the PSCDR. Two secretaries resigned and three employees were dismissed this past year.

#### **III.B. Development of the PSCDR Infrastructure**

Much effort has been given to writing procedural manuals and developing standard operating procedures in preparation for separation from the Disabled Children's Association. These procedures are now in place and the Center is ready to become independent as soon as the legalities are satisfied.

#### **III.C. Development of a Performance Enhancement System**

All PSCDR have discreet job descriptions now, which they can negotiate annually with the Administration. A formal performance evaluation will be done with each employee, setting annual goals with his supervisor. This process will be tied to merit raises in salaries. A regular ElMajlis meeting with all of the staff is held for purposes of team building and encouraging ownership of one's job. New ideas are discussed and innovations are encouraged. Merit raises will be tied to productivity and creativity.

#### **III.D. Development of a New Website for Information Dissemination**

This project was begun in 2001 and is scheduled for publication in December of 2002. It will be a major electronic resource for people with disabilities and their families, as well as for professionals in the Middle East, on topics related to disabilities. It is modeled after the very successful Family Village website at the University of Wisconsin. This is a huge multi-link database on nearly every type of disability, with information on all facets of diagnosis and treatment in the U.S. and English-speaking countries. The Middle Eastern version will provide these links for those who speak English; but it will also contain links in Arabic about resources in the Arab world that are appropriate to the Middle East. Many meetings and much development effort have been expended this past year, to make this a useful resource for people in the Middle East as they join the computer age more fully in the future. The PSCDR is dedicated to being a leader in the Middle East on information technology for future generations. The future of our communications technology is likely to be in computer and cell phone technology.

## IV. Core Services

### IV.A. Overview

The mission of the PSCDR Core Services is to provide a broad base of technical support to the research and related (e.g., outreach and dissemination) programs of the Center. By providing centralized services, the Center can promote shared solutions that are cost-effective and that enhance the performance of the Center.

The Center Administration is advocating two principles that will guide the core services in their day-to-day activities. First, scientists and staff of the Center should be in close contact with the core service operations so that staff needs drive the evolution and development of the methodologies and technologies being used by the services. Secondly, the core services should be offering a limited and focused set of support and service alternatives. That is, carefully selected solutions (e.g., software systems) should be adopted so that the broadest range of needs can be met with the narrowest (homogeneous) set of service strategies. These two principles lead to services that are cost-effective and provided by a technical staff with great competence in the services provided.

The core services of the PSCDR, as they are currently being developed, are:

1. **Administrative Services. Provides leadership and management services;**
2. **Information Technology Services. Provides information technology and database services;**
3. **Human Resources. Provides personnel services;**
4. **Media Services. Provides a wide range of services in promotional, public relations, fund-raising, and outreach and dissemination services;**
5. **Research Services. Provides support to the processes and procedures of the extramural grants program;**
6. **Dissemination and Outreach Services. Provides educational and information materials to educators, families, practitioners and persons with disabilities;**
7. **Fiscal & Accounting Services. Provides fiscal planning and accounting services.**

The management of these core services is uniform throughout the PSCDR. For each service a core service Coordinator provides administration and management within the service. Each Service Coordinator reports directly to the Executive Director of the Center. Further, each Service Coordinator sits on the Center's Executive Management Team, a team that meets weekly and is involved in the policies and procedures utilized by the Center in its day-to-day operations.

The following sections describe each of the core services and the services they provide. In addition, with each respective presentation is a proposed budget for the year 2003 (G). Those budgets are again presented in the Center Budget section as a composite budget at the end of the document.

#### **IV.A.1. Administrative Services**

(History: This was initiated as a new core service in 2002, although some of the services were provided previously by part-time staff.)

##### **Goals and Objectives**

The overall goal of the Administrative Service is to support and enhance the activities of the PSCDR by providing leadership, and by offering management and related administrative services to Center staff and programs.

##### **Description of Services**

The specific services provided by the Administrative Services include:

1. PSCDR Leadership. Leadership services are shared among the senior administrative staff of the PSCDR but are provided primarily by the Executive Director. The nature of the leadership services vary from day to day, but includes:
  - a. Program Development. The Executive Director has a primary responsibility for the stimulation and development of new research activities by new investigators and new research programs. The Executive Director is also responsible for the general direction and progress of research activities within the PSCDR.
  - b. Recruitment. A major activity of the Executive Director is to work with the Executive Committee of the Board of Trustees in the creation of new research and staff positions, and with the proper staffing of existing positions. As an example, in the last nine months, the Center has recruited six new staff. In addition, three staff have been dismissed and two resigned.
2. Management of the PSCDR. Another service of the Administrative Services is the day-to-day management of the PSCDR. This is accomplished through the administrative structures of the PSCDR. The key positions of the PSCDR's new organization, which allow it to provide these services, are the Executive Director, the Deputy Director, and the Coordinators of all Core Services. These individuals constitute the Executive Management Team, which meets weekly to address all PSCDR policies and practices.
3. Fund-raising Activities. Another service provided by the Administrative Services is support of fund-raising activities. Specifically, it is anticipated that the Executive Director will be a member of the Endowment and Research Grant Fund Committee and represent the research interests of the PSCDR in that committee's discussions. A new Steering Committee was formulated at the PSCDR, chaired by the Executive Director, meeting weekly on fund raising issues and reporting progress in fund raising to the chairman of the Endowment and Grant Fund Committee. Further, the Media Services (c.f. below) will provide technical and clerical support to the Committee.
4. Promotional Activities. Another service is to promote the PSCDR and to represent its interests to various audiences outside the Center including potential benefactors, the

scientific community, educators, practitioners, policy makers, and persons with diseases and disabilities and their families. These activities are carried out through speeches and presentations, poster presentations, membership on various advisory bodies, and attendance at a wide range of scientific meetings.

5. Clerical, Translation and Administrative Services. The Administrative Services also provides clerical support to Center staff and programs, translating services, and a range of administrative services such as purchasing and procurement, inventory, vendor identification and selection, travel, and other services as needed.

### **Anticipated Activities in the Coming Year**

Activities in the coming year are expected to focus on the following:

1. Increased breadth of scientific topics to be addressed. As described above, the PSCDR will be expanding the range of research topics to be addressed within the mission of the Center.
2. Increased level of activity and number of intramural programs. Also described above, the Center is expanding the number of intramural programs and is actively recruiting and developing the participation and collaboration of scientists in the biological, behavioral and social sciences.
3. Increased activity in the extramural research programs. The Center is anticipating an increase in the number of applications, particularly the number of fundable applications, upon the completion of its increased fiscal allocations to these activities and the implementation of timely review and funding processes.
4. Enhanced Internet presence and greater use of new technologies. The Center is anticipating a significantly increased web presence and special initiatives to develop and disseminate information to scientists, practitioners, educators, and persons with disabilities and their families.
5. More active dissemination and outreach programs. In addition to an enhanced presence on the Internet, the Center is developing and expanding its library and resource materials and recruiting a librarian/disseminator to develop expanded outreach programs.
6. Greater achievements in fund-raising. The Research Grants Committee and the Endowment Committee have been integrated into a single and focused initiative under the able leadership of Prince Faisal bin Salman. A new program and fund-raising materials are currently being developed to support these initiatives. A new Plan for Development has been written.

### **Personnel**

The personnel who make up the Administrative Services include the Executive Director, the Deputy Director, the Administrative Assistant, a Translator, a Secretary, and other clerical support staff as needed.

- Dr. Stephen R. Schroeder, Executive Director, responsible for the management of the PSCDR and all administrative functions identified in this section, (full-time).
- Mr. Ghazi AlShaalan, Associate Executive Director, and the chief associate to the Executive Director, responsible for assisting Dr. Schroeder in carrying out the administrative policies and procedures of the Center, as well as liaison with important members of the Saudi community, (full-time).
- Ms. Abeer Sumeir, Administrative Assistant, responsible for assisting the Executive Director in the administrative operations of the Center. She assists in the organization of all meetings, conferences and personnel interactions, travel, correspondence and operational support, (full-time).
- Ms. Deema Al Azhari, Translator, translates all in-coming documents and correspondence from Arabic to English for the Director and translates outgoing materials from English to Arabic, (full-time).
- Other Clerical Support Staff, including a central pool of secretaries, receptionist, and house staff, (full-time).

## **Budget**

**PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH**

**DETAILED BUDGET FOR YEAR 2003**

Proposed Duration of Project From: 01/01/2003 To: 31/12/2003

**Department/Project: ADMINISTRATION SERVICES**

**PERSONNEL**

<i>NAME</i>	<i>Months</i>	<i>% Efforts on Project</i>	<i>Annual Base Salary</i>	<i>Salary Requested</i>	<i>Total Benefits</i>	<i>Total Salary with Benefits</i>
PER ATTACHED			1,068,360	1,111,278	353,083	<b>1,464,361</b>

CONSULTANT'S COSTS Consultants Fee **150,000**

Guest Speaker's Honorarium **100,000**

EQUIPMENT COSTS

SUPPLIES COSTS **167,000**

TRAVEL COSTS **200,000**

ALTERATION AND RENOVATIONS **100,000**

OTHER EXPENSES **178,000**

**TOTAL COSTS FOR 2003 BUDGET 2,359,361**

## IV.A.2. Information Technology Services

### Goals and Objectives

The goals of the Core remain as described last year -

- to provide support throughout the PSCDR organization in connection with information technology and electronic resources,
- to provide support throughout the PSCDR organization and to specific disability researchers outside the PSCDR in connection with quantitative methods and data analysis.

As for objectives, a rough *rule-of-thumb* in the field of information technology is that a newly developed technology becomes obsolete in approximately three years. For that reason a natural timeframe for pursuit of objectives in an organization dealing in information technology is three years. It is along these lines that the following eight objectives have been set forth, and given with the objectives is a brief statement on the progress to date –

1. to recruit, retain, and develop the team,
  - to have a set of operational policies in place by 31 March 2003,
  - to recruit a full-time Research Data Manager by 30 June 2003,
  - to define the long-range staffing needs of the ITS by 30 September 2003
  - to have all key ITS staff attend at least two professional development programs by 31 December 2004,

Progress: The documentation of operational policies is under development. There is progress, especially with respect to the usage of the Internet, to the distribution of printers, and to the support of photocopiers. Work is on target for a completion of a complete set of operational policies by 31 March 2003.

2. to provide the ITS with appropriate facilities,
  - to have defined the immediate needs for information systems by 31 March 2002,
  - to have selected and installed IT resources by 30 June 2002,
  - to have facilities modification needs defined by 31 March 2003,
  - to have developed a long-term facilities plan for the ITS by 30 June 2003,
  - to have a long-range technology planning process in place by 30 September 2003,

Progress: The immediate information systems needs were defined during the past year. The Core was visited by a consultant, Dr. Fred Wightman, of the Waisman Center. In his report following his visit recommendations were made which contributed to the definition of systems needs. Associated with that was the request for purchase of a new server and some supporting hardware and software. The software has arrived, but the hardware has not yet.

3. to provide help/support in information technology and resources, and evaluate the support services offered,

- to establish the required mechanisms to provide help and support to the PSCDR staff by 31 December 2002,
- to develop a long-range plan for offering of services to the research community, the disabled, and the general public by 31 March 2003,
- to identify criteria for the evaluation of support services offered by ITS by 31 March 2003,
- to establish a mechanism for the evaluation and reporting of performance, and to encourage corrective action,

Progress: The principal effort of the ITS during the past year and that area to which the bulk of staff support has been directed is help and user support. The ITS has had a full-time staff member present in the Center to provide assistance in PC software/hardware support, in e-mail queries, in printing facilities problems, and a wide variety of other user support function. The ITS is in the process of developing criteria for evaluation of its support services.

4. to provide training in IT and resources for users in the PSCDR, the disabled and their support community, and other members of the PSCDR community, and evaluate the training services offered,
  - to develop a mechanism for the identification of initial and ongoing needs for training by 31 December 2002,
  - to implement the initial training mechanisms by 31 March 2003,

Progress: Through the King Faisal Specialist Hospital and Research Centre the ITS has connected to a series of online courses known as NETg. These courses provide tuition in the full range of Microsoft software. The speed of the software is slow as a result of the network connection, but functional.

5. to provide a national database and disabilities register, and evaluate the national disabilities information services offered,
  - to develop a mechanism for the identification of initial and ongoing needs for a national database and disabilities register by 30 June 2003,
  - to develop a mechanism for the delivery of information on disabilities and the disabled throughout the Kingdom by 31 December 2003,

Progress: No progress has been made on this objective during the past year.

6. to provide IT resources and expertise to support the administrative requirements of the PSCDR, and evaluate the administrative processing services offered,
  - to develop a mechanism for the identification of initial and ongoing needs for administrative data processing by 31 December 2002,
  - to determine the needs for the processing of administrative data by 31 March 2003,
  - to begin delivery of information to meet administrative needs by 31 March 2003,
  - to identify criteria for the evaluation of administrative data processing services by the ITS by 30 June 2003,

Progress: During the past year access to the networked file servers has been provided to all administrative staff, together with the facility for backups. E-mail and Internet services have been provided to such staff as well. An Access database system has been maintained for the Human Resources Core for storage and retrieval of personnel information. An Access database system has been maintained for the Research Services Core for tracking of extramural grant requests. Again, through the visit of the consultant, Dr. Wightman, recommendations were received on mechanisms for administrative data processing.

7. to provide mechanisms to identify, access, and respond to additional demands for services, and appropriate means for delivery of these services, and evaluate the mechanisms for the identification of additional services the ITS can provide, and the mechanism for the determination of appropriate means of delivery,
  - to develop a mechanism for the identification of needs for additional services by 31 December 2002,

Progress: This objective, though still valid, was not pursued this past year.

8. to provide senior management with regular reports on the progress of the ITS in fulfilling its mission,
  - to provide a comprehensive report on accomplishments and failures of the ITS to the Director, PSCDR, for 2002 by 31 December 2002,
  - to have established a schedule for regular reporting of progress of the ITS in fulfilling its mission by 31 December 2002,

Progress: Staff from the ITS are in attendance of a weekly meeting conducted by the Center's Director and at which reporting on progress from activities in the ITS is submitted.

### **Description of Services**

The ITS maintains a computer network throughout the PSCDR which provides to the users file and printing services. These services include daily backup of all files stored on the servers, and restoring of such files on demand. The network runs an e-mail application and some database applications. In addition, ITS links to the Internet through the Sultan bin Abdulaziz Foundation over a fast microwave connection.

The Core provides user support to the computer users of the PSCDR on a variety of stand-alone applications on the workstations, e.g. Microsoft Offices products. The Core staff respond to problems with printers, PC configuration, storage media, etc.

The ITS maintains the PSCDR Web site.

### **Other Progress to Date on IT Services**

The ITS maintained a constant staffing level during the year with 2.00 FTE staff - a 0.25 FTE Director, a 0.25 FTE Systems Analyst, a 1.00 FTE System Administrator, and a 0.50 FTE Webmaster. Job descriptions were written for these positions and for all anticipated jobs in the ITS Core. These job descriptions have been submitted to the Human Resources Core.

An objective during the year was to hire a full-time Director, and database staff. To this end, job advertisements were placed, and active recruitment efforts pursued with the result that a full-time Director, ITS has been identified, approved, and will be beginning with the Core before the end of the year. Activities are now being pursued to hire a Research Data Manager.

Significant study went into the specification of a server upgrade for the Core. The consultant, Dr. Fred Wightman, provided advise on this issue. A purchase request for the hardware has been submitted. Also the Core sought to expand its licensing of administrative software (as well as upgrade existing licenses). To this end 50 current licenses of Microsoft Office were acquired, as well as networking software which makes the Core's networking and e-mail services software current.

The interim Director of ITS served a number of administrative functions in the Center at large including memberships on the Extramural Grants Research Committee, and the Credentials Committee. He also participated in several brainstorming sessions to associated with the development of a "Family Village-like" Website for the Center.

The provision of internet services from the King Faisal Specialist Hospital and Research Centre was stopped during the year and replaced with a much higher bandwidth service from the Sultan bin Abdulaziz Foundation through a microwave connection. Associated with this new service was the need to reconfigure several systems in the Core. These included the Anti-virus server and the workstation licenses, the dial-up facility which the Core maintains, the e-mail server, and the Web server. For the latter, a Cobalt Web server was commissioned during the year which is dedicated to only Web services. It was decided that, while having to reconfigure the PCs associated with the new internet services, a upgrade to the XP platform would be carried out on all the Center's workstations. This will have been completed before the end of the year.

Associated with the higher bandwidth of the internet service, it was decided during the year to invest in the IP phone technology which now allows very inexpensive long distance telephone services through the internet for the Center. Specialized hardware were purchased to support this and were installed and configured by Core staff.

The Core added a new accounting application to its services during the year to support the needs of the Fiscal Services Core. The SPSS Statistical Software Package was acquired for support of statistical analyses of data from administration and science at the Center. Two administrative database applications - one for Human Resources and one for Research Services - were maintained during the year. In addition to these, a newly developed database of professionals was developed by Core staff.

### **Anticipated Activities in the Coming Year**

For the coming year activities are anticipated in the following general areas:

#### **PERSONNEL**

The newly recruited Director of the ITS will be charged with objectives of the Core as detailed above. The development of a comprehensive set of operational policies and procedures as described in last year's annual report and which were not completed during the past year will be a priority. To insure continuity to the operations of the ITS, the past interim Director of the ITS

will be retained as a consultant to the Director on a minimal 1/8 FTE commitment until a full turnover has been effected.

Associated with the full-time commitment of a Director will be the need for administrative support. To this end a bilingual secretary is needed and will be recruited during the coming year. This individual will be responsible for organizing the Core with respect to its documents, software media, equipment, direction of communication between the Core and other units of the Center, etc.

With the existence of research programs within the Center, data are accumulating from these programs and a Research Data Manager is needed to support this. Several candidates have been identified for this position. The successful recruitment of one of them is being pursued.

## **FACILITIES**

The Core has specified in its systems needs plan the upgrade to the network cabling capacity to 100 Mbs/second. This upgrade is anticipated in the coming year. In addition, the Core sees the increased effectiveness of specifying notebook computing technologies for Center staff, and will be aiming to start during the year the replacement of desktop computers with notebooks. Finally, there were facilities acquisitions which were specified in last year's annual report which were deferred as a result of slow recruitment, e.g. in ITS, Media Services. Those facilities (e.g. a presentation system, a database package which can support Web technology, Web development tools, scanners, and a renovation to the furniture of the ITS offices). The Core has been requested to provide Web-based e-mail services (i.e. the availability of connecting to the Center's e-mail server through a browser). The Core will be acquiring and commissioning such software during the coming year.

## **DATABASES**

The coming year will see a significant improvement in the development of electronic databases to support the administrative and scientific needs of the Center. The Director of the ITS will study the database needs of the administration, rank order their priority through consultation with the Center's Director, and ensure the development of most of them during the coming year. In addition, following the recruitment of the Research Data Manager, database development will begin on support of the needs of the Language Development Intramural Research Program.

## **TRAINING**

The NETg online courses will be continuing during the coming year through the arrangements with the King Faisal Specialist Hospital and Research Centre. The Center's administrative staff will be especially encouraged to take these courses. In addition, concerted efforts will be made to offer monthly training lectures to Center staff by ITS on subjects relevant to computing applications available at the Center, e.g. e-mail issues, MS Office issues, etc.

The staff of the ITS will again pursue attendance at meetings for their professional development. These are absolutely necessary for the staff to stay current in a rapidly progressing field. GITEX attendance for three staff is planned, as well as attendance at local conferences.

## **USER SUPPORT**

The user support activities will continue during the coming year. New during the year will be the institution of the policy of logging all user support calls and recording the concomitant information related to client's name, nature of the problem, time to solution, and nature of solution. In addition, a FAQ on the Center's Website will be further expanded as user support requests are found to cluster.

## **Personnel**

The personnel needed for activities planned for the coming year include:

- Mr. Nizar Abdulhadi, Director, to direct scientific investigations and service activities for ITS, recruits personnel to the ITS; determines equipment needs, (full-time).
- Dr. Edward De Vol, Coordinator, to provide overall direction and administration to the activities of the ITS; (part-time 25%).
- Mr. Saleh Al Ageel, System Analyst, to supervise the Center's network; to maintain existing sw/hw systems, diagnosis and repair hw problems; specify new hw solutions, (part-time 25%).
- Mr. Abdulrahman Al Thuwaini, Operations/User Support Analyst, to provide support to computer users throughout the Center on the use of office software, and networked facilities; to train users in the use of office software; [full-time (75% of the position is supported by KFSHRC)].
- Webmaster, to develop and maintain the PSCDR web site; to assist in development of strategy for the Web site, (full-time/ TBR).
- Programmer–Administrative support, to write programs to support administrative functions in the Center, (full-time/ TBR).

## **Budget**

**PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH**

**DETAILED BUDGET FOR YEAR 2003**

Proposed Duration of Project From: 01/01/2003 To: 31/12/2003

**Department/Project: INFORMATION TECHNOLOGY SERVICES**

**PERSONNEL**

<i>NAME</i>	<i>Months</i>	<i>% Efforts on Project</i>	<i>Annual Base Salary</i>	<i>Salary Requested</i>	<i>Total Benefits</i>	<i>Total Salary with Benefits</i>
PER ATTACHED		See attached	194,000	866,280	406,966	<b>1,273,246</b>

CONSULTANT'S COSTS 0

EQUIPMENT COSTS **255,000**

SUPPLIES COSTS **31,500**

TRAVEL COSTS **30,700**

ALTERATION AND RENOVATIONS 0

OTHER EXPENSES Comp.Syst.Maintenance, ISP-Microwave, DLL **211,500**

**TOTAL COSTS FOR 2003 BUDGET** **1,801,946**

### **IV.A.3. HUMAN RESOURCES SERVICES**

(History: This was initiated as a new core service in 2002, although some of the services were provided previously by part-time staff.)

#### **Goals and Objectives**

To devise and administer programs, policies, and procedures that will attract and retain employees for the Center. Human resources' functions are concerned with a variety of activities and services that significantly influence all areas of an organization.

#### **Description of Services**

The specific services provided by the Human Resource Services include:

##### **1. Compensation**

###### Staff compensation system

One area of responsibility of the Human Resource Services is the efficient and equitable administration of the Staff Compensation System for all PSCDR professional, managerial, administrative, clerical, and labor employees. More specifically:

- Managing and updating the Staff Compensation System.
- Researching and evaluating wage and salary data and trends.
- Classifying newly created and existing positions.
- Serving as an informational resource to PSCDR on compensation issues.

###### Pay Philosophy

It is important to consider both internal and external factors as pay decisions are made. Internally, importance should be placed on equity in relation to others in like jobs, to our best ability, as well as individuals' skills, knowledge, performance and job-related experience. Externally, the relevant labor market will be monitored to determine market movement, keeping in mind its effect on employees and their respective pay. Also, the employee's zone area (nationality) will be put into perspective when determining salary.

###### Pay Structure

The Staff Compensation System contains 15 job grades. Each position in the organization is classified by the Category, grade, and level into which that position falls. Within each category, there are one or more grades. The grades represent, in general, the value of each job to the organization, with higher values representing a greater value of the job to the organization. The higher value of a category is the result of superior qualifications (experience, training, and/or skills) required of the incumbents in positions within that category. As for levels, within each category, there are three levels, which again reflect the value of the positions within the category. The three levels reflect the geographical origin of the incumbents, and are based on the perceived relevance of experience and knowledge required for the position.

The Staff Compensation System covers all professional, managerial, administrative, clerical, and labor staff members. Each grade has a minimum and a maximum pay

amount. The new employee will be offered a salary based on the Center's salary structure where the salary must fall within the Center's approved annual budget.

### Job Classification

The job classification process should be conducted for either a position that is newly created or for one that currently exists but is believed by the immediate supervisor to have significant new or revised responsibilities and/or requirements. In addition, job classification includes job titles which should reflect, as clearly as possible, the nature of the work performed, and be distinct enough to differentiate the job from others. Job descriptions on the other hand specify the job's major duties; the general nature and level of work performed by incumbents, and the minimum and preferred qualifications for the job.

## **2. Employment**

### Recruiting and hiring

Services include making a list of open positions, with the assistance of each core service director, and placing advertisements. In addition, candidates will be located to fill open positions, and those candidates will be screened and interviewed for eligibility by the Ad-Hoc (hiring) committee. The application of the recommended individual to hire will be presented to the Credential's Committee for their review and approval. The final selection of the candidate to be hired will be that of the Executive Director's. Other duties include, interviewing applicants and conducting orientation for new employees.

## **3. Performance Management**

The goal of employee performance appraisals is to assist an organization in developmental objectives and growth. On average, the PSCDR employee will be evaluated twice a year. One evaluation to be conducted by the supervisor upon the employee's re-contraction, and the other is a self-performance appraisal to be conducted by the employee and reviewed by the supervisor to make proper recommendation for promotion, salary increases, and merit increases. The self-performance appraisal is a method for the employee to determine his/her objectives, goals, and accomplishments. It has shown in numerous studies that goal setting is an important element in employee motivation. Goals can stimulate employee effort, focus attention, increase persistence and encourage employees to find new and better ways to work. The Center's executive office will determine the time of self-performance appraisals.

## **4. Policies and Procedures**

Policies and procedures manual documents the practical aspects of work relationships. It will be the duty of Human Resource Services to maintain the manual in a current, complete, comprehensive manner and update manual when necessary. Also to circulate changes to the policies and procedures contained in the manual in a timely fashion and to ensure that the intent and details of all policies and procedures are understood and agreed upon by all employees of the Center.

## **5. Training and Development**

Services include administration of all training programs, as well as defining training needs, selecting training providers, and ensuring that employee records reflect training.

In addition, participating in job development, employee disciplinary programs, and career path building.

### **Progress to Date**

1. Completed the Policies and Procedures Manual of the Center.
2. Completed the salary scale.
3. Assisted in the completion of the job descriptions' manual for vacant and existing positions.
4. Evaluated and still evaluating current compensation systems for all employees and activity.
5. Filled seven (7) positions in different core services within the Center.
6. Developed employee database.
7. Assisting employees with personal problems that influence their work performance.

### **Anticipated Activities in the Coming Year**

1. Forecast the personnel requirements necessary for the organization to achieve its objectives. Develop and implement a plan to meet these requirements.
2. Ensure that this organization fulfills its government obligations.
3. Continue to select (or hire) personnel to fill the vacant positions available in all core services.
4. Develop a proper method for measuring training return and impact.
5. Implement appraising the performance of individual employees and assess outcome.
6. Increase productivity for retained employees.
7. Design and implement programs to ensure employee health, safety, and continue to provide assistance to employees with personal problems that influence their work performance.
8. Implement, maintain and update the Policies and Procedures Manual.
9. Design with the assistance of ITS an automated employee database.
10. Design with the collaboration of ITS and Fiscal Services an integrated employee payroll/compensation system between Human Resources and Fiscal Services.

### **Personnel**

The personnel in the Human Resource Services include:

Ms. Maya Rafii, Director, handles all the major functions within the core service. Conducts job analyses to establish the specific requirements of individual jobs within the organization and recruits the personnel required by the organization. Maintains and updates the policies and procedures manual; (full-time)

Secretary: Assists the HR Director in the administrative day-to-day operations of the Human Resource Services. Updates employee database on regular basis and assists employees in their basic needs. Maintains an employee filing system and coordinates with other core services; (full-time / TBR)

Government Relation's Officer: Liaisons with Human Resource Services and government sector concerning employee exit-re-entry visas, Iqama renewal, transfer, and other government related matters; (part-time / TBR)

## **Budget**

## PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH

### DETAILED BUDGET FOR YEAR 2003

Proposed Duration of Project From: 01/01/2003 To: 31/12/2003

**Department/Project: Human Resource Services**

#### PERSONNEL

NAME	Months	% Efforts on Project	Annual Base Salary	Salary Requested	Total Benefits	Total Salary with Benefits
PER ATTACHED			126,000	228,300	127,487	<b>355,787</b>
CONSULTANT'S COSTS						0
EQUIPMENT COSTS						
SUPPLIES COSTS						
			Computer Supplies			<b>4,000</b>
			Office Supplies			<b>3,000</b>
TRAVEL COSTS To attend Seminars, Symposiums (includes Airfare & Per diem)						<b>20,000</b>
ALTERATION AND RENOVATIONS (Itemize by Category)						0
OTHER EXPENSES Safe for Employees PASSPORTS, Manual Printing Etc.						<b>7,000</b>
DHL Correspondence						<b>2,000</b>
<b>TOTAL COSTS FOR 2003 BUDGET</b>						<b>391,787</b>

#### **IV.A.4. Media Services**

(History: This is a continuing core service with new leadership and support personnel.)

##### **Goals and Objectives**

The overall goal of the Media Services is to strengthen the image of the PSCDR and to act as a bridge between the Center and the public, including potential benefactors, scientists and educators, practitioners, professional institutions and associations, persons with disabilities and their families.

The specific objectives of the core service include:

1. The creation of informational materials about the PSCDR, including pamphlets, brochures, video materials needed to describe, document and promote the programs of the Center;
2. The creation of an active and on-going relationship with a network of individuals and organizations whose interests are appropriate to and aligned with the Center's mission;
3. The enhancement and promotion of public awareness of issues related to disabilities and the Center's programs in addressing those issues;
4. Assistance of the Center's fund-raising activities.

##### **Description of Services**

The services provided by the Media Services include:

1. Creation of, and access to, a contact database (e.g., names and addresses).

Media Services will provide an extensive database of contacts including researchers, educators, practitioners, professional/parent/client/consumer organizations, potential benefactors, and persons with disabilities and their families.

2. Preparation of printed informational materials as needed by the PSCDR.

These materials may be used for a wide range of uses, including information about research and other Center programs, research publications, promotional materials concerning meetings and conferences, and enhancement of public awareness about disability issues.

3. Preparation of film and other video materials.

As with printed materials, these materials may be used for a wide-range of uses. In particular, the PSCDR plans to use video materials to educate and provide information to practitioners, educators and persons with disabilities and their families.

4. Preparation of electronic presentation (e.g., via MS PowerPoint) materials.

Primarily as a service to the staff of the PSCDR, Media Services assists in the development of materials to be used in scientific presentations.

5. Participation in promotional and scientific meetings (e.g., exhibitions, festivals, etc.)

Media Services provides personnel to represent the Center, such as staffing a booth, at exhibitions and related gatherings.

6. Organization of annual functions that recognize individuals and events in the field of disabilities.

Media Services assists in the planning and development of functions designed to enhance public awareness of accomplishments of individuals and organizations, and to bring attention to disability issues.

7. Preparation and publication of articles for the public media (e.g., newspapers) and establishment of T.V. programs that may focus on research on disabilities.

Media Services works closely with major media outlets, including newspapers and television stations in the development and presentation of information related to disabilities.

8. Provide staff and assistance to the Endowment and Research Grant Fund Committee as they pursue their fund-raising efforts.

### **Anticipated Activities in the Coming Year**

1. Prepare new materials about the programs and initiatives of the PSCDR, including brochures and pamphlets. These materials will describe the new research initiatives and grant-support activities of the Center.
2. Develop new promotional materials about the Center for use by the Endowment and Research Grant Fund Committee.
3. Pursue the establishment of a National Disability Day in the Kingdom dedicated to the enhancement of the lives of persons with disabilities.
4. Plan for the development of a documentary film about the PSCDR and its contributions to disability issues in the Kingdom.
5. Sponsor a national, one-day scientific seminar on a topic of relevance to the research programs of the PSCDR.
6. Continue to provide all the services identified above in the support of PSCDR researchers and staff.

### **Personnel**

Mr. Waleed Al-Deaigy, Director, to provide management and coordination, (full-time);

Bi-lingual secretary, to support the activities of the Department, (full-time/TBR);

Mr. Anwar Al-Qahtani, Editor (English), to provide editorship and writing support in English, (full-time);

Editor (Arabic), to provide similar services in Arabic, (full-time/TBR);

Mr. Haytham Al-Ageel, Coordinator, coordinates, arranges, and prepares all necessary requirements for activities of Media Services, (full-time);

Audiovisual technician (senior), to assist in the development of media materials, (part-time/TBR);

Audiovisual technician, similar to senior technician, (full-time/TBR);

Photographer, to provide photographic services, both digital and regular, (part-time/TBR);

Technician, general duties, (full-time/TBR);

Journalist, to provide journalistic support, (part-time/TBR);

Journalist, to provide journalistic support, (part-time/TBR).

### **Budget**

## PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH

### DETAILED BUDGET FOR YEAR 2003

Proposed Duration of Project From: 01/01/2003 To: 31/12/2003

**Department/Project: MEDIA SERVICES**

#### PERSONNEL

<i>NAME</i>	<i>Months</i>	<i>% Efforts on Project</i>	<i>Annual Base Salary</i>	<i>Salary Requested</i>	<i>Total Benefits</i>	<i>Total Salary with Benefits</i>
PER ATTACHED			306,000	786,300	420,725	<b>1,207,025</b>
CONSULTANT'S COSTS						0
EQUIPMENT COSTS						<b>42,000</b>
SUPPLIES COSTS						<b>20,000</b>
TRAVEL COSTS						
ALTERATION AND RENOVATIONS						0
OTHER EXPENSES		Communication				<b>650,000</b>
<b>TOTAL COSTS FOR 2003 BUDGET</b>						<b>1,919,025</b>

#### **IV.A.5. Research Services**

(History: This is a continuing core service department, but with a mission more focused on the extramural research program.)

##### **Goals and Objectives**

The overall goal of the Research Services is to provide support to the PSCDR in the establishment of the annual research priorities as well as in the administration and processing of research grant applications. It also provides staff support to the Research Committee of the PSCDR.

##### **Description of Services**

1. Participate in defining the priorities for the annual research program.

As part of the Annual Extramural Research Grant Program, the PSCDR conducts public meetings to accept the recommendations of the public in the establishment of the Center's research priorities. The Research Services conducts these meetings and reports on their outcome.

2. Administration and processing of extramural grant applications.

The Research Services is responsible for the administration and processing of all extramural research grant applications. These services include the review of applications for completeness, entry of information about application and principal investigator into databases, support of the peer-reviewer selection processes, communication with reviewers and members of the Research Committee, and provision of clerical and administrative support to the Research Committee during the review committee meetings.

3. Continued monitoring of extramural research projects.

The Research Services provides the support for the on-going monitoring and administration of extramural grants. These services include communications with the P.I.'s, review of progress reports, and, in conjunction with the Outreach and Dissemination Services, arrangements for reporting and public dissemination of information about extramural research grant projects to concerned groups or individuals.

##### **Progress to Date**

The Center received a total of 24 applications for the Seventh Annual Research Program (2001-2002). For the first cycle, the Center received a total of 14 applications (the deadline was on October 15, 2001). Two of the 14 applications were excluded from the extramural review process. Of the 12 applications remaining, 6 have been approved for funding and the Center and each individual Primary Investigator have signed a contract. The remaining 6 applications were advised to resubmit their applications on the next deadline (April 15, 2002) contingent on the Research Committee's feedback.

### **Anticipated activities in the Coming Year**

The Center is anticipating the receipt of approximately 45 extramural research applications in the year 2003. Similarly, a comprehensive review process will ascertain their scientific merit. In subsequent administrative processes involving the Research Committee and the Science Committee, some number of those applications will be selected for support. The administrative processes associated with that review and funding decisions, and the on going monitoring of all extramurally-funded research programs, will occupy the staff of the Research Services.

### **Personnel**

The Personnel needed to carry out the duties and activities of the Research Services include:

Dr. Abdulrahman. M. Abouammoh, Director, to supervise all activities of the unit, to oversee and administer the review of proposed research projects, and to follow-up and oversee currently-funded research programs, (part-time).

Ms. Sarah K. Samman, Grant's Administrator, to implement all activities associated with the receipt, review and fund applications. This individual must maintain files and databases, be responsible for peer-review and committee review activities, communicate with Research Committee and peer reviewers, and facilitate all communications with scientists, (full-time).

Mr. Adel Awad Mohammed, Secretary, to provide clerical support, including Arabic typing, and to provide clerical support to the Research Committee, (full-time).

### **Budget**



#### **IV.A.6 Outreach & Dissemination Services**

(History: This is an expanded core service department that incorporates previous services provided by part-time staff.)

##### **Goals and Objectives**

The goals and objectives of the Outreach and Dissemination Services are to form and develop the infrastructure for collecting, archiving and disseminating information related to disabilities. In so doing, the service seeks to establish a comprehensive physical and electronic library in the area of disability, with a focus on Arabic materials. Finally, the Service aspires to the establishment of active avenues of communication and cooperation between the PSCDR, practitioners, educators, scientists, individuals with disabilities and their families.

##### **Description of Services**

1. The provision of information to a wide audience in the area of disabilities.
2. The dissemination of results of research conducted either by Scientists at the PSCDR or in extramural research projects supported by the Center.
3. The provision of referral information and resources to families regarding services and support for persons with disabilities available in the Kingdom.
4. The conduct of a wide range of educational activities including seminars, workshops, journal and discussion groups, and national and international meetings.

##### **Accomplishments During Past Year**

1. Archival Publications

For a list of archival publications published by PSCDR scientists in the years 2001-2002, see pp. 84-90.

2. Community Awareness.

Several activities related to the promotion of community awareness were carried out by the department during the last year. These activities were carried out via telephone contacts as well as consultations on-site. These consultations addressed a range of topics, including provision of scientific references and research materials, advice on functions and activities of daily living for persons with disabilities and their parents, and availability and location of services provided to the people with disabilities.

3. Scientific meetings (Seminars, Symposia, and Conferences)

Many scientific programs were hosted and/or conducted by this service during the past years. They were:

- Al-Shammary, Tarsh: Local Experience with Autism in the Kingdom of Saudi Arabia.

- Schroeder, Stephen R. and Dolan, Terrence: Fundamentals of Grantsmanship
- Ozand, Pinar: Genetics Workshop 2002 for Geneticists in Saudi Arabia
- Shriver, Anthony: Best Buddies International: A Program for Friendship Formation for People with Disabilities.

### **Anticipated Activities in the Coming Year**

The activities planned by this service for the upcoming year are:

1. Creation and development of a Scientific Research Library & Information Database.

This service will develop a number of databases designed to manage the large amounts of data that are planned to be collected, archived and disseminated by Center. These include: book database, research articles database, services/centers database, resources (Internet, CD-ROMs, Handouts, Workshops, Flyers ... etc.)

2. Develop a logging system for calls.

In order to document and quantify community needs and accurately predict where the Center should focus its informational materials, a comprehensive call-logging system will be established. The system would include call identifying information, date request was made, type of information requested, date information was given to the caller and the type of information given. The logging system will be networked so that all involved parties are notified when information is requested and when information is sent out.

3. Inventory of all materials currently held at the PSCDR.

A new library room will be designated and all current printed materials at the Center will be moved to that facility, organized, and archived in a database that will be networked and available to all employees of the Center. A related goal is to minimize the amount of paper used in the Center. A document scanner will be used to archive journal articles and other materials. This will allow for reduction of storage space needs and will enhance our ability to transmit data electronically.

4. Increase the amount of resources available at the Center.

An effort will be made to expand the collection of materials at the Center, with a focus on contents that may be available from local and international libraries, Universities, Professional Associations and Organizations. These materials will be reviewed and the most pertinent resources will be purchase or acquired and archived for the Center. The remaining resources that are not purchased will be archived and available as bibliographic lists for interested parties.

5. Develop a computer network.

In order to support the above activities, a computer network linking the library and dissemination/community outreach division members needs will be developed. The

network will be established utilizing existing computers in the Center and with proposed new computers for the library facility.

6. Develop a priority list.

A list will be created of all disability service providers in the Kingdom. A survey assessing the services of each provider will be developed, distributed and the results analyzed. Based on this analysis, the Center will create recommendations regarding service needs for persons with disabilities and their families.

### **Personnel**

The following staff is responsible to carry out the activities of the Outreach and Dissemination Services:

Dr. Sulaiman Al-Shammari, Director, to oversee and manage the staff and programs of the department (part-time)

Mr. Siraj Mohammed Bijle: Librarian/Resource Manager, to carry out many of the activities planned for the future Electronic Library (full-time).

Dr. Heidi Alaskary, Researcher, to assist in the activities of the library (part-time).

Secretary: to provide secretarial assistance and co-ordinate and support activities (full-time/TBR).

### **Budget**

**PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH**

**DETAILED BUDGET FOR YEAR 2003**

Proposed Duration of Project From: 01/01/2003 To: 31/12/2003

**Department/Project: OUTREACH & DISSEMINATION SERVICES**

**PERSONNEL**

<i>NAME</i>	<i>Months</i>	<i>% Efforts on Project</i>	<i>Annual Base Salary</i>	<i>Salary Requested</i>	<i>Total Benefits</i>	<i>Total Salary with Benefits</i>
PER ATTACHED			150,000	205,500	60,043	<b>265,543</b>
CONSULTANT'S COSTS						
EQUIPMENT COSTS						<b>255,000</b>
SUPPLIES COSTS						<b>383,500</b>
TRAVEL COSTS						
ALTERATION AND RENOVATIONS						
OTHER EXPENSES						Communication
<b>TOTAL COSTS FOR 2003 BUDGET</b>						<b>904,043</b>

#### **IV.A.7. Fiscal & Accounting Services**

(History: This is a core service initiated in 2001.)

##### **Goals and Objectives**

The goals and objectives of the Fiscal and Accounting Services are:

1. To provide to the management of the Center with up-to-date and accurate financial information.
2. To provide support in managing financial resources available to the Center.
3. To serve as a management tool for each core service head in the interpretation of sources and uses of funds, for each research laboratory to determine the feasibility of generating or raising funds.
4. To act in advisory capacity to core services coordinators including the research program coordinators at the King Faisal Specialist Hospital & Research Center, who are conducting research for the PSCDR.
5. To participate and play an active roll in the implementation of an integrated financial management system of PSCDR.

The specific objectives are:

1. To develop and implement a computerized financial accounting system for the PSCDR that would enable this service to supply accurate financial data on demand by the management, to analyze the financial status of all the core services of the Center and for any given time period.
2. Planning and preparation of the budget for the Center for the coming year.
3. Evaluation of all the requests for disbursements and commitments of funds, including equipment purchase requisitions, in order to verify the availability of funds and to ascertain the adherence to the policy of PSCDR, before it is presented for approval.
4. To streamline procedures for the various tasks associated with cost, in the acquisition, movement, depreciation, disposal and replacement of capital assets as well as receiving of cash and disbursements.
5. Establishment of a depreciation system for equipment and other depreciable assets of the Center and capture all the accumulated depreciation for the past years, in order to arrive at the net book (depreciable) value of the assets.
6. Implementation of a budget control system for each project to monitor and measure the performance against the pre-defined goals and objectives.
7. Establishment of a pure ACCRUAL basis of accounting and eliminate the practice of cash or mixed basis of accounting, in accordance with FASB (Financial Accounting Standards Board).

## **Description of Services**

### **1. General Accounting & Financial Services.**

- Receives requests for funding or allocation. Reviews, analyzes and recommends for approval of payments to the Executive Director.
- Gathers statistical data, from within the Center and from the Disabled Children's Association, needed for financial reports and for presentation in the meetings.
- Sends notification to Research Programs and Core Services on their operational financial requirements.
- Follows up the budget or funding needs of PSCDR, until its final approval.
- Establishes cost codes for research grant entities.
- Maintains books of research grant account, extramural and intramural programs.
- Establishes methods and accounting procedures in accordance with AICPA (American Institute of Certified Public Accountants) and FASB (Financial Accounting Standards Board), as applicable and/or needed.

### **2. Payroll Services.**

- Evaluates, calculates work hours, vacation hours, sick time off hours and other hours taken with or without pay, from the time sheets submitted to the Fiscal and Accounting Services.
- Calculates wages, salaries, per diems and other cash benefits for employees as and when required.
- Salaries and wages are calculated and transferred to the respective Bank accounts of the employees every month.
- A complete record of the employee's payroll is updated and is available up on request.

### **3. Payable Services.**

- Vendor's invoices would be processed for payment.
- In case the employees or the consultants have purchased some goods for the Center, the reimbursement for those items would be processed.
- Request for cash advance in order to purchase items for the Center would be processed.

### **4. Planning & Budgeting Services.**

- Internal operating budget program will be introduced to control PSCDR'S budget at all levels on continuous basis.
- Fund needs would be planned and forecasted on regular intervals, based on actual consumption of funds in previous periods and future needs, keeping in mind the introduction of new trends and technology in research on disabilities.
- Budget for every aspect of the Center would be prepared and sent for approval to the Board of Trustees.
- After the approval of the budget, it would be allocated to the respective entities, on a percent basis, depending on the total amount of the budget approved, for the period.

- Request for additional budget/funds would be submitted if the need arises.

5. Financial Control & Internal Audit Services.

- Develop policy for financial control of PSCDR.
- Introduce audit program in accordance with GAAS (Generally Accepted Auditing Standards), to ascertain that the fiscal policy of the PSCDR is adhered to.
- Report and correct discrepancies.
- Implement measures to guard against the misuse and overuse of the Center's funds.

6. Purchasing Services.

- Verify purchase requisitions, issue P.O., and transmit to the Vendor.
- Process vendor's invoices for payment and issue checks.

**Anticipated Activities for the Coming Year**

- Since the legal separation of the Center from Disabled Children's Association is under-way, once the Center becomes independent, Fiscal and Accounting Service would take total charge of complete Accounting and Fiscal Services.
- Since the Balance Sheet of Prince Salman Center for Disability Research was not available from the Disabled Children's Association, the comprehensive accounting software could not be put to use. Outlook beginning year 2003 appears to be challenging. Fiscal and Accounting Services team is striving to establish a uniform policy of funds disbursement. After the data transfer into the Center's comprehensive software, Accounting and Fiscal Services would be in a better position to use the software in its full capacity to satisfy the requirements of the management of the Center.
- All the financial statements and reports required by the Center's administration, including but not limited to cash flow statement, statement of sources and uses of funds, the balance sheet, trial balance and general ledger report will be prepared.

**Personnel**

To implement these services, the following personnel are needed:

Mr. Masood Khan, Director, to provide overall direction and administration, to guide, train and coordinate the activities of the service, (part-time);

Mr. Khalid Al-Qarni, Accountant, to run and maintain the accounting system and the daily activities of the department, including the daily treasury responsibilities, (full-time);

Mr. Ahmed Al-Dweesh, Accountant, to assist in coordinating the research projects, and to facilitate the principal investigators of the projects, (part-time);

Mr. Aslam Raei, Secretary, to support accountants and the director of the service of the daily routine in all aspects, (full-time).

**Budget**



## **V. LONG-TERM CONSIDERATIONS OF THE PSCDR**

As the PSCDR prepares for the development of future programs and activities, there are several areas and topics where attention is needed. These remain the same as they were in 2002. They include:

### **V.A. Expansion of Research**

As described in Section II.A.4 (Programs in Early Planning Stages), there are several areas of research that the PSCDR is hoping to incorporate into our activities in the coming years. These areas of research cover a wide range of topics in the biological, behavioral, and social sciences in most cases, we will strive to develop both intramural and extramural research programs related to those topics.

There are two additional areas of research not cited in Section II.A.4 that might be included in the present discussion. Both areas of research are of high priority to the PSCDR. The first addresses issues in the general area of learning disabilities. The topic of learning disabilities is extraordinarily broad, and there are few areas of science in which expertise is not needed as we strive to understand this disabling condition. At present, there are particularly interesting hypotheses being investigated concerning the role of genetic mechanisms in the causes of learning disabilities. Also, there is much conjecture concerning the impact of exposure to environmental toxins early in development in Saudi Arabia, although there are no explicit epidemiological data available, it is clear that the incidence of learning disabilities is high among the children in the Kingdom.

The second area concerns Fragile-X Syndrome. Fragile-X Syndrome is now the most frequent cause of genetically-determined cognitive disabilities in many countries in the world. Again, although epidemiological data are not available in the Kingdom, there is much evidence to suggest it is a significant cause of cognitive disabilities. In the United States, Fragile-X Syndrome is now a special focus of research at the U. S. National Institutes of Health. However, research initiatives in the United States may or may not be particularly relevant to understanding this disease in Saudi Arabia and the Middle East. As in many other conditions (e.g., cystic fibrosis), the mutations and genetics mechanisms responsible for the disease, and the most effective treatments, may be quite different in the Kingdom than elsewhere. This disease would be particularly relevant to the mission of the PSCDR in our efforts to understand and effectively treat childhood diseases and disabilities.

Finally, these are but two examples. As the Center's resources increase, and as progress in science uncovers new research opportunities, the PSCDR remains in a position to undertake new initiatives. The committees of the Center, particularly the Research Committee, are in excellent positions to monitor the activities of science and to advise the Center regarding new opportunities.

There are other, non-research related topics of significant importance to the PSCDR as we prepare for the next several years. They include:

## **V.B. Relationship with the Disabled Children’s Association**

For the first nine years of its existence, the PSCDR has been an organizational component of the Disabled Children’s Association (DCA). In that capacity it served as the research unit of the Association. The relationship between the PSCDR and the DCA has been a productive one. It was actually because of the fiscal and administrative support the PSCDR received from the DCA that the Center was created and developed.

However, now that the PSCDR has gained increased autonomy, with full-time leadership and expanded research programs, it is important for the Center to gain a new level of independence. To that end, we recommend strongly that the PSCDR become a completely independent organization with its own Charter, Bylaws, and a completely separate fiscal identity.

The separation of the two organizations will allow the PSCDR to develop and implement policies and procedures more appropriate for a research institution than for a service-providing institution; it will allow the Center to distinguish itself more completely in public arenas; it will allow the Center to conduct a media campaign promoting exclusively the PSCDR’s programs; and it will allow the PSCDR to conduct a more-effective fund-raising effort and develop a separate endowment. All of these accomplishments are crucial to the Center’s development and should be priorities for the immediate future.

## **V.C. Fund-Raising Initiatives**

A related issue of great importance to the PSCDR is the generation of resources to support the Center’s programs. In 2001 two committees of the PSCDR, the Research Grant Fund Committee and the Endowment Committee were merged into a single committee. Recently, they have been separated again. The Endowment Committee is charged both with the development and management of an endowment dedicated to the support of the Center. The Research Grant Fund Committee will develop of a gift fund. The latter would provide funds directly to specified research programs and projects – both intramural and extramural. The continuing limitation of resources, and the lack of sufficient funds to support our research programs, dramatically constrains the opportunities facing the Center as we pursue our goals.

## **VI. SUMMARY STATEMENT**

This report constitutes a “progress report” of the many activities that have been initiated during the past year at the PSCDR. We believe that the new initiatives in the intramural research programs, the extramural research programs, modifications in our organizational format and the development of new core services, are significant. The Center stands on the threshold of important opportunities – opportunities that have the potential to make an extraordinary contribution to the Kingdom. In the end, we believe that the primary beneficiaries of our efforts will be persons with disabilities, the persons who service them, and the families of those with disabilities. They are the object of our efforts; they are the objects of our hopes and aspirations.

**COMPOSITE BUDGET FOR 2003**

**PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH**

**DETAILED BUDGET FOR YEAR 2003**

Proposed Duration of Project From: 01/01/2003 To: 31/12/2003

**Department/Project: SUMMARY OF TWO (2) ONGOING INTRAMURAL RESEARCH PROGRAMS**

**PERSONNEL**

<i>CATEGORY</i>	<i>Months</i>	<i>% Efforts on Project</i>	<i>Annual Base Salary</i>	<i>Salary Requested</i>	<i>Total Benefits</i>	<i>Total Salary with Benefits</i>
PAYROLL			914,580	1,010,578	670,271	<b>1,680,849</b>
CONSULTANT'S COSTS						<b>93,218</b>
EQUIPMENT COSTS						<b>61,200</b>
SUPPLIES COSTS						<b>244,200</b>
TRAVEL COSTS						<b>41,330</b>
ALTERATION AND RENOVATIONS						
OTHER EXPENSES						<b>396,808</b>
Genetics of Neurosensory & Neuromuscular Diseases Proj. supported by KFSH&RC						<b>(1,215,148)</b>
<b>TOTAL COST SUMMARY FOR 2003 BUDGET 2 RESEARCH PROGRAMS</b>						<b>1,302,457</b>

**PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH**

**DETAILED BUDGET FOR YEAR 2003**

Proposed Duration of Project      From:      01/01/2003      To:      31/12/2003

**Department/Project:      PROPOSED NEW NEWBORN SCREENING PROGRAM**

**PERSONNEL**

<i>NAME</i>	<i>Months</i>	<i>% Efforts on Project</i>	<i>Annual Base Salary</i>	<i>Salary Requested</i>	<i>Total Benefits</i>	<i>Total Salary with Benefits</i>
PER ATTACHED			1,575,972	1,575,972	725,826	<b>2,301,798</b>

CONSULTANT'S COSTS 0

EQUIPMENT COSTS **1,488,000**

SUPPLIES COSTS **2,335,000**

TRAVEL COSTS **100,000**

ALTERATION AND RENOVATIONS 0

OTHER EXPENSES      Communication **10,000**

Existing Equipment Maintenance **500,000**

**TOTAL COSTS FOR 2003 BUDGET 6,734,798**

**PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH**

**DETAILED BUDGET FOR YEAR 2003**

Proposed Duration of Project From: 01/01/2003 To: 31/12/2003

**Department/Project: SUMMARY OF SEVEN (7) CORE SERVICES**

**PERSONNEL**

<i>NAME</i>	<i>Months</i>	<i>% Efforts on Project</i>	<i>Annual Base Salary</i>	<i>Salary Requested</i>	<i>Total Benefits</i>	<i>Total Salary with Benefits</i>
<b>PAYROLL</b>			3,296,080	3,681,144	1,584,418	<b>5,265,562</b>
<b>CONSULTANT'S COSTS</b>	Consultants Fee					<b>269,000</b>
	Guest Speaker's Honourarium					<b>100,000</b>
<b>EQUIPMENT COSTS</b>						<b>552,000</b>
<b>SUPPLIES COSTS</b>						<b>614,000</b>
<b>TRAVEL COSTS</b>						<b>360,700</b>
<b>ALTERATION AND RENOVATIONS</b>						<b>100,000</b>
<b>OTHER EXPENSES</b>						<b>1,198,500</b>
<b>TOTAL COST SUMMARY FOR 2003 BUDGET SEVEN (7) CORE SERVICES</b>						<b>8,459,762</b>

**PRINCE SALMAN CENTRE FOR DISABILITY RESEARCH**

**DETAILED BUDGET FOR YEAR 2003**

Proposed Duration of Project From: 01/01/2003 To: 31/12/2003

**Department/Project: EXTRAMURAL RESEARCH PROJECTS**

TOTAL ENCUMBRANCE ON NINE (9) APPROVED PROJECTS 1,911,592

EXPECTED PROJECTS APPROVAL DURING THE YEAR (ADDITIONAL) 2,000,000

**TOTAL COSTS FOR 2003 BUDGET 3,911,592**

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## **ABSTRACTS**

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