

2001 Retrospective

SICKLE CELL DISEASE ASSOCIATION OF AMERICA INC.

Congressman Ralph Regula (R-OH) Chair of the House Labor - HHS - Education Appropriations Subcommittee ponders testimony from SCDAA President/COO, Lynda K. Anderson during one of many visits to the Hill in pursuit of the National Advocacy Program initiative.



Congressman Jesse Jackson, Jr. (D-IL) prepares to respond to personal testimony offered by 2000-2001 SCDAA National Poster Child Tahira Givhan on the need for increased funding for research and patient services

LEADERSHIP MESSAGE FROM THE PRESIDENT/COO & BOARD CHAIR

LYNDA K. ANDERSON
President/COO



KATIE G. DORSETT, ED.D.
Chair of the Board



NO YEAR-END RETROSPECTIVE CAN BEGIN WITHOUT FIRST SAYING THANK YOU to all who believe in and support our mission to promote finding a universal cure for sickle cell disease and improve the quality of life for individuals and families where conditions related to sickle cell disease exist.

On the list are those who support SCDAAs and its Member Organizations through Community Health Charities, foundations, organizations, and individuals. We especially thank those corporate sponsors of our 29th Annual Convention for allowing SCDAAs to apply their sponsorships to other program areas in the wake of September 11th and subsequent cancellation of the conference. And we thank the leadership and citizens of our country, for demonstrating just what "United We Stand" truly means.

We are also pleased to report that initiatives, designed to strengthen our National and Member Program areas while bringing more resources to the entire sickle cell community, are moving forward with encouraging success. The centerpiece is our National Advocacy Program. Following a concerted campaign of letter writing, petition gathering and legislative interaction, an unprecedented increase of \$4 million dollars was provided to newborn screening projects that are funded by the Health Resources and Services Administration (HRSA) and its division of Maternal and Child Health (MCH).

The initial funding, slated for Fiscal Year 2002, will support the establishment of a National Coordinating and Evaluation Center that will assist, monitor and evaluate the coordination of community-based SCD screening, education and health care related services. The funds will also support fifteen community-based demonstration sites and institutions across the country that would provide SCD patient support services, trait follow-up and other outreach services. The funds will make a significant contribution to national data coordination, follow-up, counseling, treatment interventions and outreach efforts.

SCDAAs is moving forward with our education and advocacy initiative for Fiscal Year 2003 as well as focusing on other strategies to best utilize resources provided by our supporters. Thank you for helping us "Break the Sickle Cycle."

In the year 2001, SCDAAs marshaled a successful education and awareness campaign resulting in an unprecedented \$4 million dollar increase in funding for newborn screening activities and follow-up projects.

CHIEF MEDICAL OFFICER YEAR END REPORT

STEM CELL TRANSPLANTATION

Exciting things are happening as we advance toward a cure. Stem cell transplantation has already been demonstrated, on a limited basis, to cure sickle disease. Efforts are underway to try to overcome some of these limitations such as the donor having to be related to the recipient (preferably a sibling) and the match having to be nearly perfect. The successful cure of sickle cell disease using banked cord blood from an unrelated donor and the engraftment of related donor cells might be sufficient to ameliorate the disease, should extend the possibility of transplantation to a larger number of patients.

GENE THERAPY

Gene therapy, though not having yet been tried on patients with sickle cell disease, looms large as the eventual cure. It is being studied in patients with diseases such as cystic fibrosis and hemophilia. In sickle cell disease, laboratory investigation and pre-clinical studies in transgenic mouse models are moving at a rapid pace. It is expected that clinical trials in sickle cell disease will be warranted within 5 years.

Success of gene therapy requires a gene transfer vehicle capable of efficiently causing (transducing) donor stem cells to permanently correct the genetic alteration by site-specific integration into the host and resultant restoration of normal functioning.

The most effective vectors (vehicles for carrying the curative gene), to date, have been viral and primarily 3 types: Adenoviruses, retroviruses and lentiviruses. The latter represents an effort to exploit beneficial properties of a potentially deadly virus, HIV-1 into a small de-activated portion that is a safe carrier of the cure for a disease that can be devastating and debilitating. Efforts to find and confirm safe, effective vectors continue.

PHARMACOLOGICAL THERAPIES

Regarding pharmacological therapies, we have much good news but it is also grimly astounding. The good news since 1998 has been the FDA approval of hydroxyurea and its use for the

LENNETTE J. BENJAMIN, MD
Chief Medical Officer



prevention or lessening of the occurrence of acute painful episodes, acute chest syndrome and blood transfusion requirements in some patients with sickle cell disease. The astounding aspect of that is that in approximately 100 years of recognition of sickle cell disease in the western world, hydroxyurea is the only drug approved for treatment of sickle cell disease.

As we focus on future care and cures for sickle cell disease, we have much to do to accelerate the process of discovery as to which therapies work best and give us the hope for a breakthrough. We must advocate for a network of clinical treatment and research centers to facilitate the coordinated prioritized effort to provide an array of treatments that can control or attenuate the disease while we search for a universal cure. Crucial to such

efforts will be the enhancement of translation of research and clinical practice. A program to fund post-doctoral research fellows has been established to have a direct impact on the cutting edge of research as we also continue to pursue our promotion efforts through advocacy and action. These researchers will commit themselves to sickle cell disease and will be working to discover ways to arrive at a cure.

The SCDA National Counselor Certification Initiative remains a high priority. If we are to service patients in a manner that affords them dignity and parity with others with inherited disorders, we must have properly credentialed individuals, who know how to educate, counsel and comfort. They must be trained in the basics and must keep pace with advances that require or impact upon effective education and counseling. As we provide standards and a common denominator for the quality of our education/counseling staff and increase the potential for clinical and translational research through advocacy and research programs, we have increased hope and promise for a cure, better care and improved quality of life.

Our mission is to promote finding a universal cure for sickle cell disease and improve the quality of life for individuals and families where conditions related to sickle cell disease exists.

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VISIT OUR WEBSITE WWW.SICKLECELLDISEASE.ORG

2001 SCDAА CONDENSED FINANCIAL STATEMENT - DONOR LIST

Functional Expenses as a Percentage of Total Expenses

Technical Assistance	\$ 212,096
Education	433,394
Research	165,832
Administration	128,252
Fundraising	71,451
Total Expenses	\$ 1,011,025

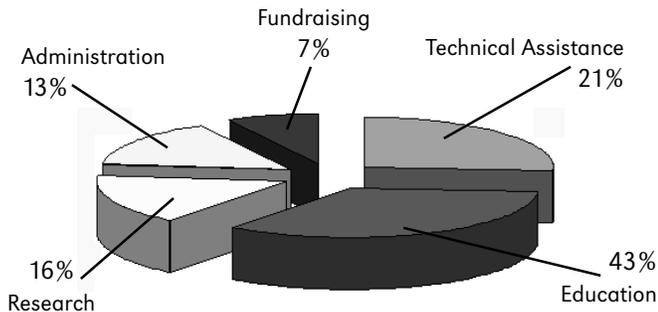
Expenses as a Percentage of Revenue

Revenue		Amount
		\$ 817,825
Expenses		
Tech	\$ 212,096	
Ed	433,394	
Research	165,832	Program 811,322
M&G	128,252	
F/R	71,451	Support 199,703
Total Expenses		1,011,025

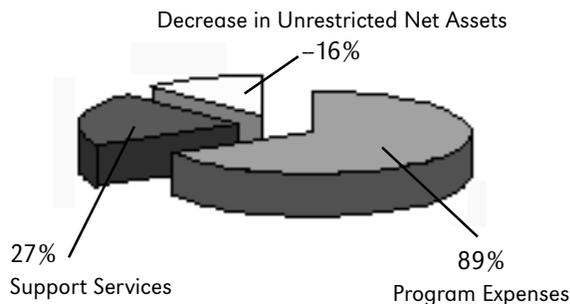
Revenue Less Expenses

Program Expenses	\$ 811,322	Decrease	(193,200)
Support Services	199,703		
Decrease in Net Assets	(193,200)		

Functional Expenses as a Percentage of Total Expenses



Expenses as a Percentage of Revenue



2001 DONORS

Sickle Cell Disease of America, Inc. and those we serve thank the following corporations, foundation and organizations that joined the thousands of public support contributors who gave in memoriam, through legacies & bequest or as individuals to support research and other National programs and services in 2001.

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SCDAA NATIONAL PROGRAMS AND ACTIVITIES

National Programs and Services

Public Health Education—On the National level, SCDAA has played a major role in the movement to bring accuracy and consistency to the content of public information regarding sickle cell disease. In 1973 the Association's first publication, "A Critical Review of Informational Materials Relating to Sickle Cell Anemia and Sickle Cell Trait" examined the inaccuracies and unduly alarming statements about sickle cell conditions that were appearing in many publications available to the general public. Following that example, SCDAA, under the guidance of its Medical and Research Advisory Committee, publishes and distributes a variety of educational materials, including bilingual fact sheets, brochures, videos, and VIEWPOINTS, a newsletter for patients and families to help them understand breaking developments in research and treatment, that have become invaluable tools for community education. In a variety of formats ranging from health fairs to seminars, newborn screening follow-up to school-based activities, SCDAA Member Organizations are the community-based link to services for the sickle cell population. SCDAA Member Organizations conduct educational programs and distribute literature to the general public, public and private school systems, civic organizations and health care providers.

Screening services are offered to individuals of childbearing age and pre-marital couples to determine their hemoglobin status. Counseling services are offered to all individuals screened and found to have a hemoglobin variant. The purpose of counseling is two fold; first to communicate the risk of occurrence or recurrence of the disease and second, to communicate the medical facts, including diagnosis, probable course of the disease and the available management and resources.

Professional Health Education

The emphasis of SCDAA and its Member Organizations on professional health education takes many forms. SCDAA sponsors professional educational programs at its annual convention with participation of the Comprehensive Sickle Cell Centers and NHLBI. The meeting offers a unique opportunity for health care providers and researchers to interact with community-based organizations, consumers and policy makers in a learning environment. SCDAA Member Organizations also organize and conduct professional education programs for health care providers in their service areas. Most of these activities are done in collaboration with the Member's local treatment or research centers. These activities are invaluable



exercises in narrowing the gap and strengthening the collaboration between consumer and provider. SCDAA also continues its work toward standardizing knowledge and practices of sickle cell hemoglobinopathy counselor/educators through the establishment of a National Counselor Certification Program.

Patient Services

SCDAA Member Organizations offer a multitude of patient services including: tutorial services, transportation assistance, emergency financial assistance, food and clothing distribution, summer camp and hospital visitation. Referral services are also available to help patient's access medical, psychosocial and other support as needed. Patient services are enhanced by the collaborative efforts of the Comprehensive Sickle Cell Centers and other medical centers affiliated with SCDAA. These activities and relationships are all efforts to aid in improving the quality of life for those with sickle cell disease and their families.

efforts of the Comprehensive Sickle Cell Centers and other medical centers affiliated with SCDAA. These activities and relationships are all efforts to aid in improving the quality of life for those with sickle cell disease and their families.

Research Support

SCDAA and its Member Organizations have a long and unprecedented history in research support. From 1984-1987 the SCDAA supplied unrestricted grants to support ongoing studies at the 10 NIH supported Comprehensive Sickle Cell Centers; established a Sickle Cell Summer Research Apprenticeship program to give African American high school graduates research laboratory experience and to stimulate them to pursue scientific careers; and, awarded grants to Meharry Medical College and Charles R. Drew Medical School to support sickle cell research projects. Member Organizations have given direct grants for research in their local communities and continue to work with researchers in clinical trials by supplying valuable patient data and follow-up. In 1999 SCDAA demonstrated its commitment to biomedical and psychosocial research with the development of a Post-Doctoral Fellowship Program aimed at developing young scientists beginning their research academic careers. The Program has 6 participants to date.

Community Service

SCDAA and its Member Organizations engage in community outreach efforts throughout the United States and Canada. Activities include health fairs, testing, counseling, referral, participation in National Sickle Cell Awareness Month, scholarship programs, special educational programs targeting students and the ongoing development of an interactive global community and resource base via the SCDAA website.