

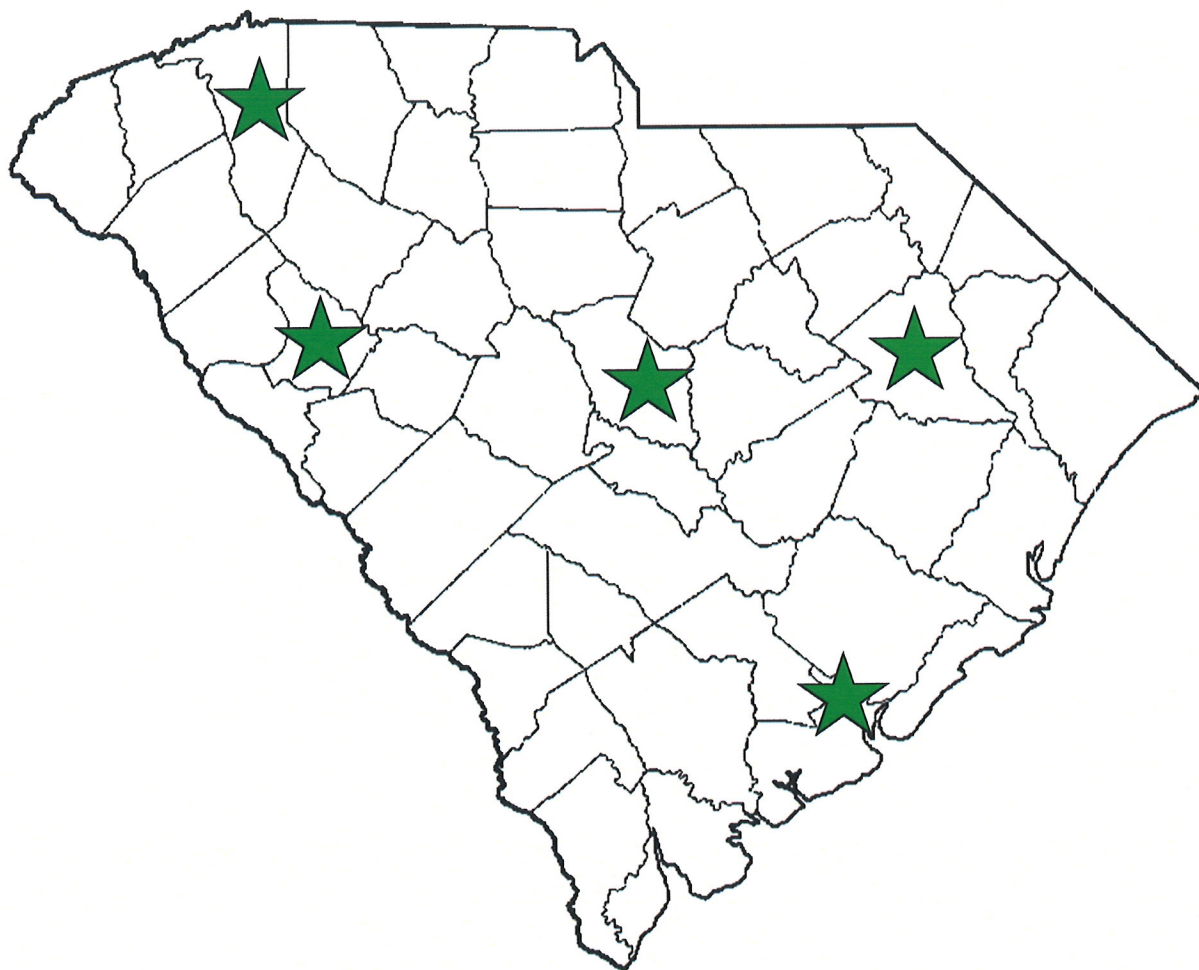


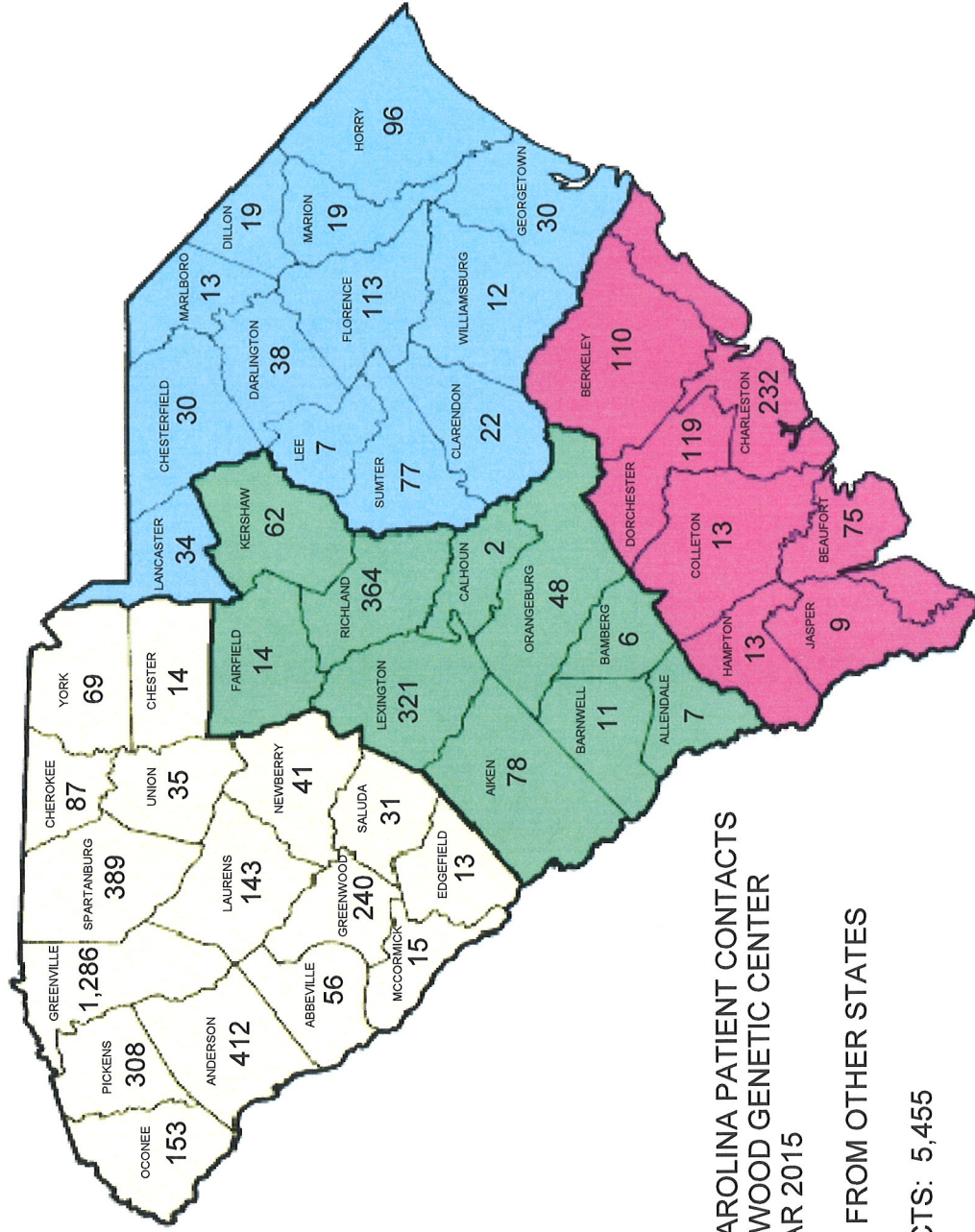
Greenwood Genetic Center

Where Compassion Inspires Progress

Presentation for the
South Carolina
House Ways and Means
Subcommittee on Healthcare
February 2, 2016

Greenwood Genetic Center Office Locations



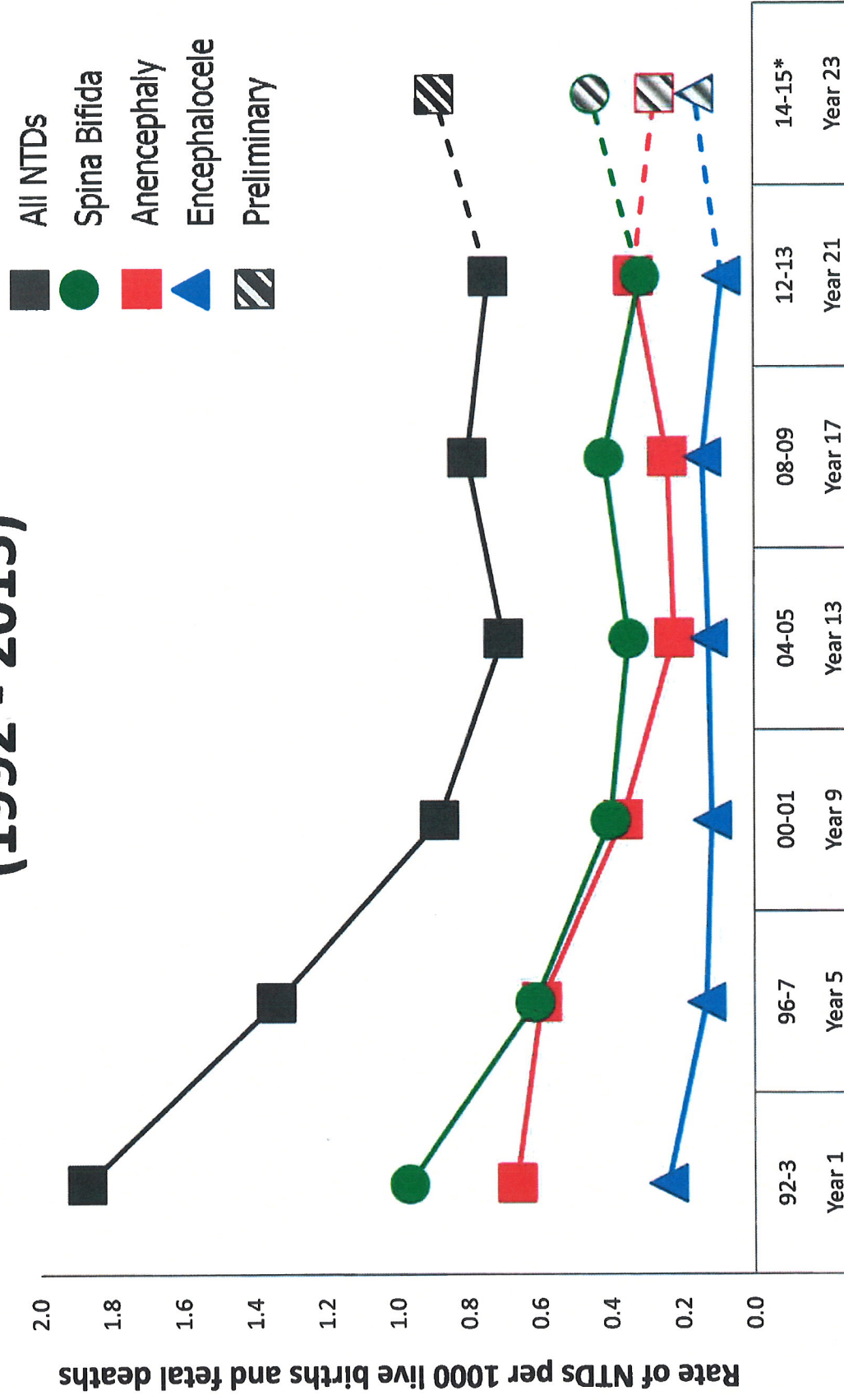


5,287 SOUTH CAROLINA PATIENT CONTACTS
BY THE GREENWOOD GENETIC CENTER
CALENDAR YEAR 2015

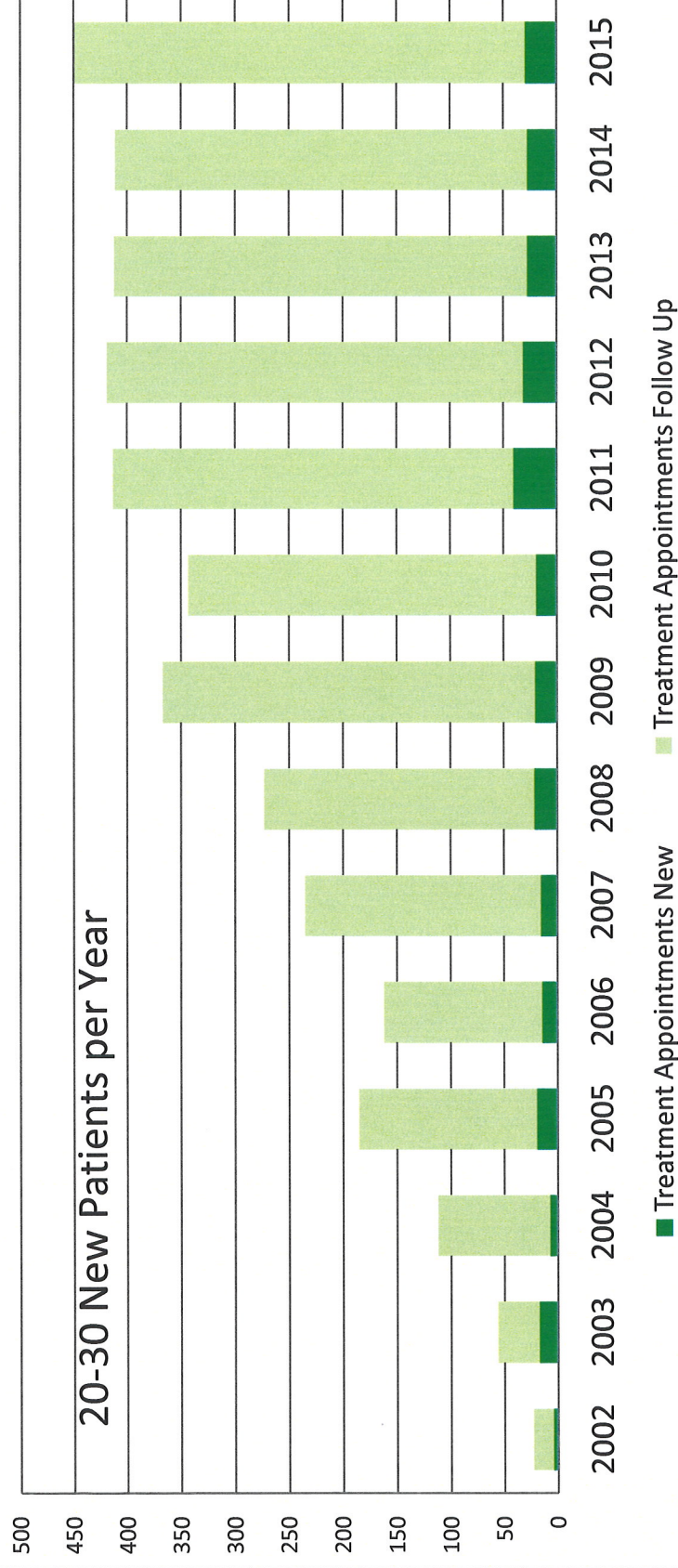
168 CONTACTS FROM OTHER STATES

TOTAL CONTACTS: 5,455

NTDs in South Carolina (1992 - 2015)



Metabolic Treatment Program New and Follow-up Patients





The Greenwood Genetic Center carries out the Major Disability Prevention Programs for the South Carolina Department of Disabilities and Special Needs

The financial impact of the DDSN-GGC Prevention Programs:

	State Funds	Federal Medicaid Funds	Total Funds for Services	Annual Medical Cost Savings
Birth Defects of Brain and Spine Prevention	\$289,300	\$289,300	\$578,600	>\$25,000,000
Metabolic Treatment	\$1,266,070	\$2,573,555	\$3,839,625	>\$40,000,000
Genetic Services	\$1,595,000	\$3,833,151	\$5,428,151	>\$15,000,000
Autism Research	\$200,000	0	\$200,000	???
Totals	\$3,350,370	\$6,696,006	\$10,046,376	>\$80,000,000

The Greenwood Genetic Center leverages the approximately \$3,000,000 in State funds with federal and foundation grants, fees and other income, into a \$21,500,000 total annual budget used in the evaluation, treatment, and prevention of disabilities in South Carolina. These efforts prevent more than 75 cases of disability in infants and children each year, and the overall medical cost savings are estimated to be over \$80 million annually.

Successful Prevention Programs of the SC Department of Disabilities and Special Needs and the Greenwood Genetic Center Partnership

The SC Department of Disabilities and Special Needs (DDSN) and the Greenwood Genetic Center (GGC) have partnered for over forty years to develop a comprehensive approach to make genetic evaluations, testing, treatment and prevention services accessible for families in South Carolina.

Prevention of Defects of the Brain and Spine (Neural Tube Defects). In 1992, just months after the discovery that folic acid supplementation in women can prevent serious birth defects of the brain and spine, DDSN partnered with the GGC to begin a program to educate the population and prevent these defects. Now hailed as one of two model programs in the nation for the prevention of neural tube defects, the SC efforts have decreased the occurrence of these defects in our state by nearly 60%. This means that each year 60 babies in South Carolina are

now born healthy that, prior to this program, would have had a neural tube defect. In financial terms, this means over \$25 million is saved every year in health care costs.

Metabolic Treatment Program. With the support of the General Assembly the Newborn Screening Program conducted by DHEC was expanded to thirty-three genetic conditions in 2004. DDSN maximized this opportunity to assure that all infants would receive the complex care necessary to avoid disabling consequences of these disorders. DDSN works in collaboration with DHEC, DHHS and the GGC for the systematic management and monitoring of these children.

The Metabolic Treatment Team, consisting of medical geneticists, genetic counselors, dietitians, psychologists and biochemical laboratory geneticists, currently diagnoses and treats over 200 individuals within SC. In addition to averting human suffering, these treatments save approximately \$40 million per year in medical costs through the early diagnosis and prevention of these debilitating and often fatal diseases.

Other Prevention Programs. The GGC also operates other prevention programs supported by DDSN. By identifying the causes of disabilities where preventive treatments do not yet exist, focused genetic counseling can educate families on the recurrence risk and provide options to improve the chances of a healthy baby.

In 2009, DDSN partnered with the GGC to establish the South Carolina Center for the Treatment of Genetic Disorders which serves as the state center for all of the treatment and prevention programs and gives visibility to the fact that a growing number of developmental disabilities may be prevented by early detection and treatment.

Additionally, long before the public began to focus on autism, DDSN initiated an effort in South Carolina to find the causes of autism and to stimulate efforts with the GGC toward a diagnostic test and curative therapy. This foresight has allowed South Carolina to capitalize rapidly on scientific breakthroughs in this disability that impacts 1 in 68 children.

About the Greenwood Genetic Center

The Greenwood Genetic Center (GGC), founded in 1974, is a nonprofit organization advancing the field of medical genetics and caring for families impacted by genetic disease and birth defects. Through its home campus in Greenwood, South Carolina, as well as offices in Charleston, Columbia, Florence and Greenville, clinicians and scientists provide clinical genetic services, diagnostic laboratory testing, educational programs and resources, and research in the field of medical genetics with a focus on intellectual disability, autism and birth defects. GGC's faculty and staff are committed to the goal of providing compassionate care and developing preventive and curative therapies for families across South Carolina.

For additional information from the Greenwood Genetic Center visit www.ggc.org or contact the Office of the Director, Dr. Steven Skinner, 864-941-8164 (toll-free 1-888-442-4363), email: sas@ggc.org.

For additional information from DDSN, contact Lois Park Mole, 803-898-9743, email: LPMole@ddsn.sc.gov.

GREENWOOD GENETIC CENTER 2016-2017 BUDGET NEED

GOALS

- Maintain and expand statewide access to prevention, diagnosis, and treatment services to reduce the prevalence and impact of genetic disorder, enhance quality of life, and achieve long-term cost savings
- Sustain and maximize economic contributions of Greenwood Genetic Center for the State

2015-2016 UPDATE

The additional funds allocated last year have enabled Greenwood Genetic Center to:

- Validate a blood-based diagnostic test for autism that would allow early diagnosis and early intervention for this condition that affects 1 in 68 children. At the current pace, we hope to have a blood test ready for use by the end of state fiscal year 2016.
- Expand genetic services in Florence and the Pee Dee region of the state. A genetic counselor has been recruited and will be located in Florence full-time by June. We are interviewing for a clinical geneticist who will also be located in Florence pending successful negotiations.

2016-2017 BUDGET NEED

We are seeking the balance of last year's funding request for the upcoming fiscal year to further enhance genetic services across the State.

1. Autism Treatment Program Development (\$500,000)
Based on research and preliminary findings, Greenwood Genetic Center wants to support the development of an Autism Treatment Team dedicated to creating specific treatment regimens and monitoring program for children diagnosed with autism via the blood-based diagnostic test.
2. Expansion of Metabolic Treatment Program (\$300,000)
In addition to the ongoing expansion in Florence and collaborations with Francis Marion University regarding educational and internship opportunities in medical genetics, there is demonstrated need in the Columbia service area to establish a third Metabolic Treatment Team composed of a Clinical Biochemical Geneticist, a dietician, a neuropsychologist, a genetic counselor, and a clinic coordinator to better address and service the needs of patients and families in the Midlands.
3. Maintenance of Effort (\$300,000)
New knowledge and technologies in genetic testing and treatment are constantly developing at an increasingly rapid pace. This funding will allow Greenwood Genetic Center to remain at the forefront in genetic testing, prevention, and treatment of disabilities and prevent jobs and revenue from leaving the State.

Request for Augmentation of State Funding for FY 2015-2016 for Genetic Prevention Services through the South Carolina Department of Disabilities and Special Needs

Since its founding in 1974, the Greenwood Genetic Center has had a close relationship with the SC Department of Disabilities and Special Needs. The Center has established a statewide presence to assure that genetic evaluation and testing are available for families served by DDSN. The collaboration with DDSN has been essential in every major treatment and prevention initiative at the Greenwood Genetic Center. Families statewide have benefited from the close collaboration between GGC and DDSN.

Two examples will suffice. DDSN and GGC established the SC Birth Defects Surveillance and Prevention Program in 1992 to prevent severe birth defects of the brain and spine. This very successful program has reduced and maintained the rate of these defects by over 60% with annual savings in medical costs of over \$20 million. DDSN and GGC established the SC Metabolic Disease Treatment Program in 2002 to assure that all babies found on newborn screening to have a genetic metabolic disease receive prompt curative therapy. This very effective program has over 100 children on active treatment protocols and is estimated to save over \$40 million in medical costs annually.

In order to further enhance genetic services for disabilities in South Carolina, we request an increase in state funding of \$1.765 million dollars for the following uses:

1. Metabolic Treatment and Genetic Counseling Programs - \$600,000. With this funding
 - a) A third metabolic treatment team (Clinical Biochemical Geneticist, dietitian, neuropsychologist, clinic coordinator) will be formed and located in the GGC's Columbia office. Due to the success of the Metabolic Treatment Program, referrals have increased and resulted in insufficient time available for the two current treatment teams to manage these complex medical conditions. The number of children in the Program today far exceeds the original estimate when the program was created.
 - b) A Clinical Geneticist, genetic counselor, and clinic assistant will be placed in the Florence office which is currently served only by traveling genetic teams. This region has been underserved for years. In 2013, 437 patients from this 13 county region were

served in comparison to 3,476 patients from the 16 county Upstate region and 911 patients from the 10 county Midlands region.

(We anticipate that the \$600,000 will be matchable – for some activities at 2:1 and for others at 3:1 ratio.)

2. Replacement of Autism Proviso - \$600,000. The Greenwood Genetic Center has benefited over the past 2 years from an Autism Proviso (\$500,000 each year) to further the development of a blood test for autism. This blood test based on blood cells utilization of the amino acid tryptophan for energy has been developed, is relatively inexpensive to perform, and has >90% sensitivity in young children with autism aged 1 – 10 years. The test is now being challenged with 300 additional samples from children with autism and age matched controls. As this progress in effect converts the biology of autism into a biochemical pathway, we need now to direct our energies to putting in place the strategy and infrastructure for treatment by manipulation of this pathway with drugs or diet in much the same way we treat other metabolic diseases. It is anticipated that moving into the treatment phase will require an additional \$100,000 in expenses annually. With knowledge that the current Proviso mechanism of funding cannot last, we request replacement of this funding with a state appropriation.

3. Replacement of Greenwood County Funds - \$265,000. During the past decade, Greenwood County has provided \$265,000 per year to compensate for the shortfall in state funds available for the delivery of genetic services statewide. This funding has now come to an end and we request state funding in order to maintain the genetic services that will benefit families with disabilities throughout the state.

(We anticipate the \$265,000 in state funds to be matchable at 3:1 for the provision of services.)

4. Scientific Equipment and Instruments - \$300,000. The Greenwood Genetic Center is responsible for providing genetic services statewide for persons with disabilities. Laboratory testing is essential in providing these services. It has become critical that the laboratory equipment and instruments utilized in the genetics field be upgraded continuously in order to stay current with the latest diagnostic technology that can have a life altering effect on the children involved.

(We anticipate the \$300,000 in state funds to be matchable at 3:1 for this purpose.)