



# Greenwood Genetic Center

Where Compassion Inspires Progress



## ANNUAL REPORT 2020-21

## Dear GGC Friends,

I hope this message finds you well.

As we all continue to navigate the ongoing pandemic, we wanted to take this opportunity to update our friends and donors on the amazing work that continues to happen every day at the Greenwood Genetic Center. While these past 18 months have challenged us all, the GGC team has pulled together in ways that make me so proud to be associated with this caring and talented group of scientists, clinicians, and educators. Our faculty and staff have continued to go above and beyond, not only in continuing to provide high quality care for our patients and their families, but also in leading growth and innovation that will support both our patients and our organization for many years to come.

I am personally very grateful that you continue to see the value in our mission through your support of the Greenwood Genetic Center Foundation. Through your generous giving, you are a critical component of GGC's growth and progress, and have been vital to our successes over the past 47 years.

In the pages of this annual report are statistics that reflect the hard work of the GGC team - broad numbers that provide an overview of the patients seen, tests run, and students served. We've also included stories of how your passion for GGC's mission is directly touching the families we serve. Your gifts are funding research breakthroughs, modernization of lab testing, and the inspiration of our future genetics workforce.

One recent initiative of which I am very proud is the GGC Cares Fund (p. 4). This fund, which is supported through annual giving to the GGC Foundation, is directly providing genetic services and testing to families who are unable to afford them. GGC has always worked diligently to ensure that all patients have access to the genetic services and testing that they need, regardless of their ability to pay. With the addition and growth of the GGC Cares Fund, we are not only providing direct support to families who need it most, but are also ensuring the continued financial security of the Center.

My hope is that after you have finished this report, you will feel pride in your association with GGC. Your generosity and support are appreciated far more than we can express in these pages. We are honored that, of all of the worthy organizations doing terrific work, you have chosen to lend your support to us. We remember that each and every day, and on behalf of the entire GGC team and those we serve - thank you!

With deepest gratitude,



Steve Skinner, MD  
GGC Director

## Our Mission

*The Greenwood Genetic Center is a nonprofit institute organized to provide clinical genetic services, diagnostic laboratory testing, educational programs and resources, and research in the field of medical genetics.*

## Our Vision

*The Greenwood Genetic Center will be a Center of Excellence in Medical Genetics, serving as a resource for all persons who need genetic services or information, and working to reduce the prevalence and impact of genetic disorders.*

# Our Impact

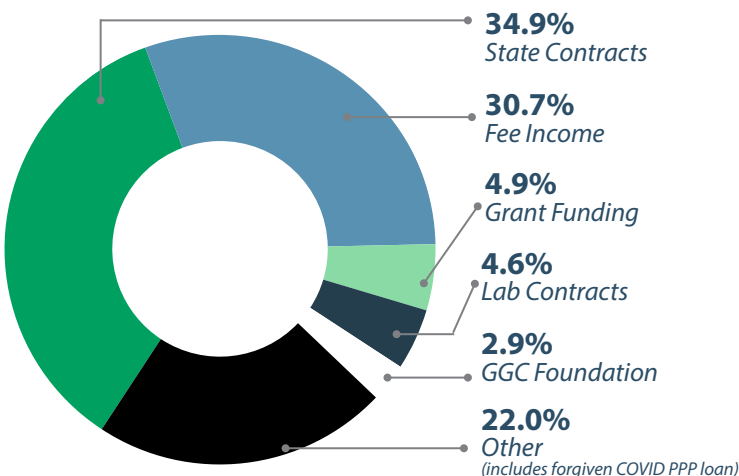
The Greenwood Genetic Center is committed to offering compassionate care to all families across the lifespan who are impacted by genetic disorders. With the ongoing pandemic, we continued to use telegenetics appointments for a significant number of our patients, though using appropriate safety measures, we also brought many patients back into the clinic. At-home sample collection kits allowed genetic testing to continue, and our zebrafish didn't even realize anything had changed! Your gifts to the GGC Foundation have allowed us to continue to provide genetic care and hope to families across our state and around the world when they needed it most.

## In 2020-21, your generosity helped us to:

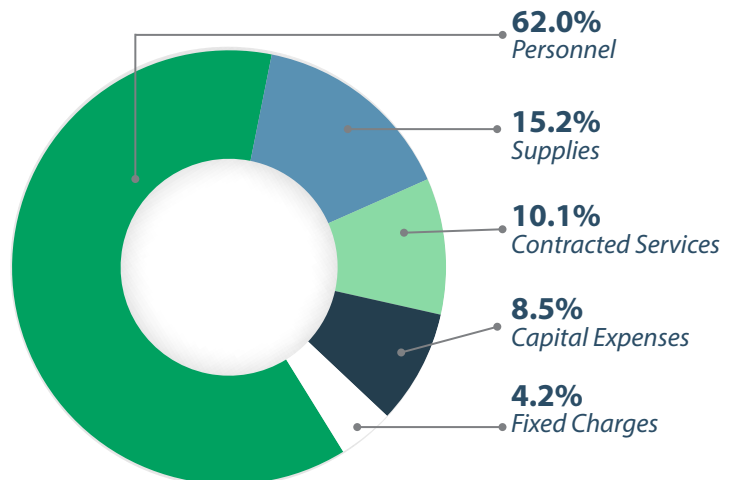
- Serve **5,140** clinical patients (**2,290** in person and **2,850** through telegenetics);
- Complete **28,935** laboratory tests to find long sought-after answers for patients;
- Prevent **70** neural tube defects through the SC Birth Defects Prevention Program;
- Coauthor and publish **75** scientific manuscripts to share our advances with the broader medical community;
- Inspire **1,387** students through **29** mobile lab trips and **11** virtual classes, **20** teachers in our summer course, and **24** students through our high school camp;
- Initiate **26** functional research studies in cells and zebrafish to clarify uncertain genetic testing results. This led to **12** definitive answers and **3** new targets for treatment; and
- Bring in **\$1.4M\*** in grant funding through **2** clinical projects, **4** NIH grants and **4** private foundation grants.

\*Highest level of grant support in the past decade.

## GGC Annual Budget



**Income (\$28.2M)**



**Expenses (\$24.3M)**

All annual statistics reflect activities from July 1, 2020-June 30, 2021, GGC's most recently completed fiscal year.

# GGC Cares Fund Provides Hope and Answers

Compassionate patient care is at the very heart of the Greenwood Genetic Center - extending beyond just the manner in which we treat our patients to the very provision of and access to genetics services. The new GGC Cares Fund fills a void for many patients in need of financial assistance.



For 47 years, the Greenwood Genetic Center has led efforts to improve access to genetic evaluations and state-of-the-art testing for all patients. These goals have been realized throughout the years by the addition of satellite offices and telegenetics to make geneticists more geographically and technologically accessible to patients across South Carolina.

Another challenge has been the ability for patients to get the genetic testing that they need. Through long-term partnerships with the SC Departments of Disabilities and Special Needs, Health and Human Services, and Health and Environmental Control, genetic testing costs are covered for subsets of patients including those with intellectual disability or metabolic disorders. For others, their insurance plans cover these important tests. But for many across our state, especially those who are uninsured or under-insured, the costs can be prohibitive.

Through the years, GGC has made sure that if testing is believed to directly impact a patient's medical management, they get it, regardless of their ability to pay. That led to exceptional patient care, but also financial strain on the organization. In 2020, the GGC Foundation launched the 'GGC Cares Fund' designed to directly support qualifying patients in getting the advanced testing that can provide long-awaited answers and hope for an improved quality of life.



Dr. Steve Skinner assesses a patient in the Greenwood clinic

Through this fund, GGC clinicians can nominate a patient for support, and if they meet criteria, some or all of the cost of genetic testing will be covered. The first distribution of funds occurred in June, covering a \$900 bill for a patient who needed next generation DNA sequencing. Three other patients have been approved for funding with testing planned, and several other families are at preliminary stages in the process. To date, thanks to your generosity, the GGC Cares Fund has raised over \$50,000 to offset the cost of genetic testing for families in need!

Our patients face many personal challenges that come with having a child with a genetic disorder - the emotional, physical, and mental tolls can be great. How wonderful that through the GGC Cares Fund, your gifts can help us alleviate this particular financial burden for our most vulnerable families.

To learn more about the GGC Cares Fund, contact the GGC Foundation at (864) 388-1801. To make your tax deductible gift, visit [www.GGC.org/foundation/donate](http://www.GGC.org/foundation/donate) or use the enclosed envelope.



## Race the Helix

*The events were virtual, but the impact is very real!*

The 6<sup>th</sup> annual Race the Helix - Upstate and 11<sup>th</sup> annual Race the Helix - Greenwood events were held fully virtually this year to protect the health and safety of our participants, supporters, and volunteers. While we missed seeing our friends in person, we had tremendous support with record-setting sponsorships and participation from around the globe - from SC to California, Great Britain, and France! Thank you to all who participated and to these very generous sponsors...

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# Donor Spotlight

## *In Memory of Dianne Patricia Leary*

Dr. and Mrs. Julius L. Leary, Jr., Lynne Leary Lovett, and Kathie Leary Marsh have established the Dianne Patricia Leary Fund for Charcot-Marie-Tooth (CMT) Neuromuscular Disorders at the Greenwood Genetic Center with a generous gift to the GGC Foundation in memory of their sister who passed away in April of 2020.

Around age two, Dianne Leary began showing symptoms of a neuromuscular disorder, which remained undiagnosed for many years, though clinical features suggested a form of CMT. CMT comprises a varied group of disorders that cause damage to the peripheral nerves that transmit information and signals between the central nervous system and the rest of the body.

There are dozens of genes that can cause CMT, and numerous subtypes have been identified. GGC was only recently able to confirm Dianne's diagnosis of CMT by identifying two gene variants using next-generation sequencing and research technologies available at the Center.

"Dianne's determined spirit allowed her to live a productive and independent life," said Dr. Leary. "She influenced and inspired friends, colleagues, and family members with her passion and creativity. Her life is an example to everyone how using your gifts can maximize your life's ambition."

The Learys' gift is already being used to further research into neuromuscular disorders like CMT. GGC researchers recently published an article reporting a novel variant in *AIFM1*, a gene known to cause CMT4X, and the team is pursuing further functional studies looking at patient skin cells to identify other causative variants in this gene.

GGC's clinic space in Greenwood has also been named 'The Leary Clinic' in Dianne's memory.

"It's fitting that patients who come to GGC will see Dianne's name when they enter," said Dr. Leary. "Her perseverance and drive should serve as an inspiration to all who seek care at GGC to never allow a genetic disorder define who you are and what you can achieve."

"We are humbled to be the recipient of this generous gift to honor Dianne's life through medical research," said Steve Skinner, MD, GGC's Director. "We commit our expertise and the latest technologies available to the better understanding of neuromuscular disorders, including CMT, to ensure that future generations of patients have quick and clear diagnoses and clear paths for treatment."



*This photo of Dianne, taken by close friend, Caroline Jenkins, was part of the Palmetto Portraits Project and was displayed at the SC State Museum.*

## Going Out on a LIMS

*Grants and GGC donors support acquisition of updated Lab Information Management System*



*Erica Cervenka (front) and Tamara Chandler review test orders as samples arrive in GGC's diagnostic lab.*

GGC will be launching a new state-of-the-art Laboratory Information Management System (LIMS) in early 2022 thanks to the support of grant funding and private philanthropy. The Self Family Foundation has provided \$250,000 to the GGC Foundation for the new LIMS with an additional \$200,000 contributed by private donors. Mutual of America Financial Group has also provided a generous gift toward this project.

GGC leads the way in diagnostic testing by employing the latest advances in genetic technologies, but has used the same lab management software for many years. As these new testing technologies generate larger amounts of genomic data and the labs are working with a growing volume of samples, ensuring quality and accuracy with the results is paramount.

The new LIMS system will manage each step in the diagnostic workflow - from the ordering of a test in the clinic until results are delivered to the family. It automatically performs quality control checks throughout the process, ensuring that all steps are completed properly and in a timely manner. Dashboard views of each sample's status allow laboratory directors to monitor the operation of each lab and address any issues before they impact the test results.

LIMS will also import data and results directly into the medical record, avoiding manual entry and the possibility of human error. This will also allow the process to flow more smoothly and efficiently, getting the much needed answers back to the providers and the families sooner.

# Thank you!

On behalf of GGC's faculty and staff, our patients and families, and all who are served by GGC we express our deepest gratitude for these individuals, families, and organizations who support the Center's life-changing work.

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