Forty years ago, a small group of committed individuals joined together to build an organization dedicated to the search for treatments and a cure for a little-known disorder called neurofibromatosis, or NF. That group established what is now the Children’s Tumor Foundation (CTF). During its forty-year history, CTF has served as a beacon of hope for NF patients and caregivers, guiding NF clinical care and research to a place of tremendous progress. Thanks to these early pioneers, today we stand at the precipice of the first potential FDA-approved drug to treat NF.

*Continued on page 8*
As we celebrate the 40th anniversary of the Children’s Tumor Foundation (CTF) this year, we are deeply grateful to those who have come before us and established such a strong organization built upon an important mission. As I reflect upon my tenure as CTF President, I am amazed to think of what it must have been like for CTF’s first President, Lynne Ann Courtemanche, who established this Foundation along with Allan Rubenstein, MD and Joel Hirschritt, Esq. In 1978, few doctors even knew what neurofibromatosis (NF) was, and the gene mutations that cause the various forms of NF were completely unknown.

Thanks to the arduous work of pioneering NF researchers, a dedicated Board, and most importantly you, supporters of the Foundation, we have seen incredible advances in NF research and tremendous growth in our Foundation. It is because of the collaboration of a focused and continuously growing NF community that we now live in a time of great optimism for NF treatments. Management options that were unheard of in the past are now available because of the accomplishments of the Foundation and its supporters.

On so many fronts, and most critically on the research front, we are making great strides. Synodos for NF2 has completed its third year with a significant data release and an NF2 clinical candidate. Our first industry partnership is a reality and we are expanding to many more, and our upcoming NF Conference in November is expected to be the largest ever, with over 800 experts in attendance.

Even more exciting, we recently received incredible news from AstraZeneca and Merck that the MEK inhibitor selumetinib has attained orphan drug status from the FDA. This drug discovery is a result of CTF’s multi-million dollar investment in the NF Preclinical Consortium; your support also provided funding for the first in-human study of selumetinib. We are closer than ever to the first FDA-approved treatment for NF!

I am inspired by CTF’s accomplishments and filled with a profound sense of responsibility to carry this momentum forward. Our vision to end NF continues with ever-increasing passion. We have come so far, and while the road before us is bound to have some difficulties, I am confident that we will fulfill our mission. It is because we bind ourselves together as a united front of researchers, volunteers, parents, donors, and patients that we will lead the way.

This May, as we celebrate NF Awareness Month, let’s join together in what I call our “UN” attitude: An UNstoppable plan. An UNconventional approach. An UNtraditional perspective. An UNcommon degree of courage. As we commemorate the Foundation’s 40th anniversary, we do so with the UNbreakable spirit that we will one day End NF.

To view Annette Bakker’s speech entitled “Choose the UN in your approach,” please visit: ctf.org/UNapproach
Selumetinib Granted Orphan Drug Designation by the FDA

AstraZeneca and Merck announced in February of this year that the U.S. Food and Drug Administration (FDA) has granted Orphan Drug Designation for selumetinib, a MEK inhibitor, for the treatment of NF1. This marks another significant step on the road to effective approved treatments for NF.

Selumetinib was shown to be effective in shrinking tumors as a result of an early-stage investment that the Children Tumor Foundation made in the NF Preclinical Consortium (NFPC). The work of the NFPC demonstrated that MEK inhibitors have significant impact on tumor size in animal models—data that was instrumental in the development of a clinical trial at the National Institutes of Health (NIH), led by Brigitte Widemann, PhD. At the Foundation’s 2015 NF Conference Dr. Widemann announced that over half of the patients in the trial were seeing significant reduction in tumor size. Currently over 70% of participants in this MEK clinical trial are showing reductions in tumor size of their inoperable plexiform neurofibromas by 20-50%.

The trial has continued with positive results, and the news that the FDA has provided Orphan Drug status illustrates not only the potential of this treatment, but provides further incentives for drug companies to invest in NF-related trials.

Synodos for NF2 Data Reveals NF2 Clinical Candidate

A compound showing significant promise in shrinking NF2-related tumors has emerged from the Synodos for NF2 consortium data. This group’s rigorous drug testing laid the groundwork for the rationale for clinical trials to test a promising new compound. In addition, researchers have also identified various combinations of this compound with other classes of compounds that showed an even more drastic response in shrinking NF2-related tumors.

Exposing tumor cells to single-drug inhibitors can cause them to adapt and bypass or reactivate other growth pathways, thus resisting treatment. Synodos researchers have been working to identify other potential new pathways activated in NF2 tumors, with the ultimate goal of discovering superior drug combination therapies.

Negotiations are ongoing with a large pharmaceutical company to start a clinical trial for this compound. To honor CTF’s contract with our collaborating institutions, we are withholding the name of the compound and industry partner temporarily, however please watch for this news to be announced at ctf.org/news, and in our e-newsletter.

Established in 2014 as the first program of the Synodos model, Synodos for NF2 included researchers from 12 world-class labs and medical centers who worked together to discover novel therapeutics that will shrink or halt NF2 tumors with minimal toxicity. This successful 3-year, multi-million dollar program completed its work in April of this year.
**CTF-Funded Research** Demonstrates Important Genotype-Phenotype Correlation in NF1

Research funded by the Children’s Tumor Foundation and led by Ludwine Messiaen, PhD, professor of genetics at the University of Alabama at Birmingham (UAB), has shown that a type of DNA mutation called a missense mutation, located in a specific part of the NF1 gene, is an important risk factor for severe symptoms of NF1. This discovery will serve to improve the predictability of this condition when these specific mutations are present in an individual. This work was published earlier this year in the American Journal of Human Genetics.

Patients with NF1, or the parents of these patients, are often told to “watch and wait” as there is no way to predict the path an NF1 diagnosis will take, thereby complicating treatment options. Dr. Messiaen’s team has identified gene mutations (genotypes) and associated symptoms (phenotypes) in over 8,100 unrelated individuals with NF1. CTF invested in her promising work by providing Dr. Messiaen with the Isaac and Sadie Fuchs Genotype-Phenotype Grant in order to facilitate the discovery of additional NF1 genotype-phenotype correlations. Dr. Messiaen’s work is increasing the knowledge of the complexity and variability of NF1-associated signs.

To read more about this publication, please go to: ctf.org/genotype

"If a genotype-phenotype correlation exists for a particular mutation, it will help families have some perspective of what the future will bring, and it will help them cope with the disease."
—LUDWINE MESSIAEN, PhD

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**RARE DISEASE DAY AT THE NIH**

*By Salvatore La Rosa, PhD, CTF’s VP of Research and Development*

This year I was invited to participate in the Rare Disease Day at the National Institutes of Health (NIH), an event that brings together “Patients and Researchers – Partners for Life,” which was their slogan for the day. The event is for stakeholders involved with any rare disease, including patients, families, caregivers, advocacy groups, researchers, and clinicians.

Part of the day was spent discussing the latest advances in gene therapy and gene editing, as new paradigms are quickly emerging in these fields that promise to revolutionize modern medicine. One example currently under scrutiny is the first in-human gene editing clinical trial for Hunter syndrome.

Another topic of interest was discussed by a panel in which I was involved called “Collaborating for Successful Research.” I spoke about CTF’s Synodos collaborative programs that currently bring together more than 40 principal investigators with more than 20 different research institutions.

The day moved along with the realization that there is still a lot of work to do. I believe that if we participate collectively and help each other in the quest to fight rare disease, we will find solutions, treatments, and hope.

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**CTF Partners with Digital Science to Promote Open Data**

The Foundation’s commitment to collaboration, open data, and transparency is reinforced by a partnership with global technology company Digital Science on a new platform called Dimensions. This groundbreaking research information database aims to transform scholarly search by linking publications, grants, policy, data, and metrics for the first time.

Dimensions breaks down barriers to discovery and innovation by providing free search and citation data for 89 million publications, linking them to almost 4 million grants (totaling more than $1.4 trillion in funding), over 34 million patents, 360,000 clinical trials, and thousands of other research documents. This partnership will provide transparency on what has been funded and therefore enable more informed research decisions.
New CTF Patient Representative Training Program

The CTF Patient Representative Training Program is a new initiative designed to prepare individuals with NF and their families to participate as patient advocates. This program will help NF patients add their perspective during all phases of the research process—from the laboratory, to the clinic, to the community. Patient Advocates are trained to work with stakeholders such as researchers, research institutions, the pharmaceutical industry, the Food and Drug Administration, and patient advocacy organizations.

This online training program will educate patients about the research and drug development process, regulatory affairs, and neurofibromatosis. Activities to encourage critical thinking and patient engagement in research also play an important part in the training, and some sessions may include an in-person component. When the initial training has been completed, participants will receive a Certificate of Completion naming them as Patient Advocates of the Children’s Tumor Foundation. They will continue their involvement in the program, and will have access to an ongoing series of educational webinars.

Patient Advocates will be prepared to participate as co-reviewers and lay patient representatives for CTF’s Research Programs; join committees with experts in a clinical setting; and join CTF’s resource pool of expert patients that facilitate reciprocal communication with NF experts.

If you are interested in joining a future training, please visit ctf.org/patientengagement for more information.

LET’S DEAL WITH NF
By Onno Faber, tech entrepreneur, and engaged NF2 patient

It’s been over three years since I was first diagnosed with NF2. I always tell people how grateful I feel to have made it my full-time job to work on helping patients get the most out of their care while creating resources to accelerate the availability of treatments. To me, to “Deal with NF” means to find a way to live with it—and at the same time work on long-term solutions to eliminate the negative impact on our lives. This is not something an individual can do, it requires strong collaboration and alignment across the board. This is what I want to help facilitate with my new startup company, “RDMD.”

RDMD is a clinical research and development (R&D) platform for rare disease. We have two goals: 1) to help patients manage their own care, while 2) setting up missing research infrastructure for better, faster, and cheaper drug R&D for the longer term.

Currently, patients spend a lot of time and energy on the phone, faxing, mailing, and copying PDFs, CDs, reports, and files. We are building technology to streamline that process, so patients can send their complete profile to new doctors, view MRI scans online, and easily set up remote consultations. This will not only help patients make better decisions on care, but also generate real world data that a researcher, a biopharma company, or the FDA could use in drug development.

The NF community has been very supportive and I could not be more excited to be on this journey with you. Thank you! Let’s deal with NF!

To read more about Onno Faber and RDMD, please go to: ctf.org/news

The 2018 Global NF Conference will be held November 2-6 at the Maison de la Chimie in Paris, France. Visit ctf.org/nfconference for updates.
In late 2016, NF Dad Larry Gossard approached his State Representative, Robert Cole Sprague, about proclaiming May as Neurofibromatosis Awareness Month in the state of Ohio. Grasping how this rare disease was impacting the life of Larry’s son, Bryce Wells-Gossard, Larry’s entire family, and thousands of Ohio families, Representative Sprague introduced a new piece of legislation.

Bryce was diagnosed with neurofibromatosis at the young age of 10-months-old. He has ADHD, some difficulties in school, and some other health issues, but he is a fighter and doing well.

Yet, before the bill could pass, the legislative session ended. Representative Sprague re-introduced the bill in February 2017 and it passed the House Committee and the entire House of Representatives unanimously! Mr. Gossard testified in front of the Ohio Senate Health, Human Services and Medicaid Committee in October 2017. Ohio House Bill 45 passed the full Ohio Senate unanimously in February 2018 and was signed into law by Governor John Kasich at the end of the month.

While dozens of states approve proclamations each year during NF Awareness Month, Ohio is the first state to have a law recognizing neurofibromatosis.

In addition to inspiring and encouraging this new piece of legislation, Larry organizes an annual event, Cruise-In for a Cure, to raise money for NF research. This was a long and demanding endeavor, but Larry’s commitment to his son and to the entire NF community was unwavering.

LARRY GOSSARD
NF DAD AND HARDIN COUNTY RESIDENT

I am humbled that Ohio is the first state to pass a law declaring May as Neurofibromatosis Awareness Month, and grateful to Representative Sprague for seeing it through. This means so much to my family, especially Bryce’s mom Heather Wells and his brother Brayden Wells, to all the NF families throughout Ohio, and the entire NF community around the country.
MAY is NF Awareness Month!

Visit ctf.org to learn more about all the ways YOU can take action to End NF!

**WEAR**
our exclusive “I Know A Fighter” and “Born A Fighter” t-shirts

**SHINE**
a Light in your community and add to the growing list of landmarks that will glow in blue and green

**CHANGE**
your profile picture to one that celebrates NF Awareness

**TAKE**
a photo that gives voice to our “I Know A Fighter” theme

**TAG**
your photo(s) on social media with #EndNF

**LIKE**
Children's Tumor Foundation on Facebook

**SHARE**
exclusive NF Awareness Month graphics

**PARTICIPATE**
in an NF event in your community

**WATCH**
our NF Awareness Month Videos

**EDUCATE**
using informative fact sheets and brochures

**JOIN**
the NF Registry if you or your child has NF

**DONATE**
to fund the cutting-edge research that will end NF

**COMMUNICATE**
Spread the word and increase awareness about NF!

**NF PATIENT REGISTRY**
Help yourself. Help others. Help End NF.

You probably know people who have not yet heard of neurofibromatosis or know little about it, but they can appreciate the strength and perseverance of our NF Heroes. During the month of May, invite everyone you know to join us – share the list above and ask them to get involved. We need the world to hear us loud and clear – it is time to End NF!

And don’t forget: May 17th is World NF Awareness Day!

Download your NF Awareness Month resources at: ctf.org/nfawareness

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**“I KNOW A FIGHTER” PHOTO CONTEST**

The NF story is one full of hurdles – diagnosis, symptoms, doctor appointments, MRI scans, pain, surgeries, and/or chemo. But it is also a story of perseverance, strength, and inspiration. “I Know a Fighter” gives voice to those living with neurofibromatosis and is a reflection of the bravery that NF patients exhibit in their daily lives.

Enter the 2018 Children’s Tumor Foundation NF Awareness Month “I Know a Fighter” photo contest! Email media@ctf.org with your entry; please include a few sentences about when and where the photo was taken. Contest ends May 31, 2018.
In 1978, motivated to create the support group she was longing for, NF patient Lynne Ann Courtemanche, RN, her physician Allan Rubenstein, MD, and Joel S. Hirschtritt, Esq. founded the National Neurofibromatosis Foundation (NNFF). In the early years, the organization was managed and supported entirely by volunteers. As the Foundation grew, it also began to engage individuals and professionals with no personal connection to NF.

In 1982, only four years after the Foundation received its charter, the NNFF originated its first NF research program, awarding grants that totaled $40,000. By 1985, CTF formalized the Young Investigator Award program, which promised to attract talented young scientists to the field of NF. This constant seeding of the field with new talent is one of the primary reasons the NF research landscape has grown so rapidly over the past 40 years.

In 1984, the Foundation organized the first meeting to address the need for NF clinics and standardized patient care. Ten years later, in 1994, the NNFF Worldwide NF Clinic Network was established, and the first annual meeting of NF Clinic Coordinators took place shortly thereafter. Today, the revitalized NF Clinic Network (NFCN) works to standardize and raise the level of NF clinical care nationally. There are now 54 participating NFCN clinics that serve over 14,000 patients each year. These clinics are able to apply for CTF stipends to host regional NF symposia, so local families have access to NF knowledge and support.

On May 22, 1985, the Foundation convened the first major international scientific conference on NF. This landmark gathering in New York was the precursor to today’s annual NF Conference. Much advancement was presented at these meetings; for example, the NF1 gene was mapped to chromosome 17 in 1987, and the following year the National Institutes of Health (NIH) published the NF diagnostic criteria. The NF Conference has grown to become the most important scholarly NF scientific event in the world, with the upcoming joint global NF Conference the largest ever, expected to draw over 800 attendees.
On July 12, 1990 the discovery of the NF1 gene in the labs of Francis Collins and Ray White made headlines. Two Young Investigator Awardees, Dave Viskochil and Peggy Wallace, participated in that work and were credited with mapping the gene to 17q11.2. In 1993, two labs funded in part by the Foundation simultaneously identified the NF2 gene.

In 1992, the Foundation began a legislative initiative to include NF research funding within the federal government’s Congressionally Directed Medical Research Program (CDMRP). As a result, the Neurofibromatosis Research Program (NFRP) was established in 1996. Since its inception, more than $300 million has been designated via the CDMRP-NFRP for NF research. CTF representatives continue to advocate on Capitol Hill each year to ensure that this funding is protected.

FORTIFYING THE NF COMMUNITY

NF awareness and education has remained a fundamental activity of the Foundation from its earliest days. In fact, the inaugural newsletter of the Foundation reported a publicity campaign to be launched, and the need for an information handbook for people with neurofibromatosis. Volunteers obtained state proclamations declaring the month of May as NF Awareness Month across the country, and in 1995, the first NF website was created. That site has evolved over the years, and today www.ctf.org receives over a million visits each year.

In August of 1997, teens from around the world gathered in Utah for the first NF Camp, a program the Foundation continues to support. NF Camp celebrated its 20-year anniversary in the summer of 2017 with 100 young people in attendance, many of whom had never met another individual sharing their diagnosis.

The dawn of the new century brought an abundance of new ideas, new technologies, and even a new name for the Foundation. The NNFF changed its name in 2005, and today the Children’s Tumor Foundation (CTF) is a highly recognized international nonprofit foundation and a model for innovative research endeavors.
A series of new research initiatives were added to CTF’s grant program, which, up to that time, had maintained the Young Investigator Awards as its sole research grant mechanism. In 2006, the first-ever five year strategic plan was developed. It pinpointed gaps in NF research, which led to the launch of the Drug Discovery Initiative (DDI) to fund translational science, and the Clinical Research Awards (CRA), to fund small-scale clinical trials and adjunct studies.

On June 13, 2005, the diagnostic criteria for schwannomatosis was published, and in 2007, upon discovery of the first schwannomatosis gene, SMARCBI, schwannomatosis was added to the Foundation’s mission. CTF’s commitment to this rarest form of NF continued with the Schwannomatosis Awards program from 2012 to 2014. Additionally, in 2013, a Young Investigator Awardee from CTF identified LZTR1 as another key gene in schwannomatosis.

On April 3, 2009, the first NF Forum to bring patients and researchers together for education and community, was held in Washington, DC. The Foundation is proud to have sponsored this important symposium seven times, with an eighth NF Forum to take place on May 4-5, 2018 in Atlanta, Georgia.

SOARING TO NEW HEIGHTS

Projects that were seeded in the early days of the Foundation have grown into incredible advancements. Past CTF funding has led to more than 62 publications in top peer-reviewed scientific journals. CTF investments from 2010 to 2015, totaling $26.6 million, have attracted more than $38.4 million in follow-up funding. Additionally, to standardize the measurement of outcomes, the increasingly important REiNS (Response Evaluation in NF and Schwannomatosis) collaboration was established during the Foundation’s 2011 NF Conference.

The Foundation established the NF Registry in 2012 in an attempt to speed the development of promising new treatments and expand our knowledge of neurofibromatosis. As of today, approximately 8,000 individuals have joined, making it the largest worldwide database of individuals with NF. This resource has allowed the recruitment of over 20 clinical trials and research studies.

In August of 2013, the CTF Biobank was established to address the need for NF tissue (such as blood and tumor samples) to be made available to researchers. Over 200 tissue samples were collected in the first year alone.

BURGEONING AWARENESS AND EDUCATION

Patients are at the heart of everything we do, and CTF’s patient initiatives have evolved from education to engagement to empowerment, with ongoing media campaigns, advocacy initiatives, and a host of patient resources on all types of NF and its manifestations available in print and for download at ctf.org.

The Children’s Tumor Foundation has expanded its celebration of the month of May as NF Awareness Month with its Shine a Light campaign, in which monuments and buildings light up in CTF blue and green to spread NF awareness. On May 17, 2014, Niagara Falls glowed blue and green for the first time, and hundreds of buildings, bridges, and monuments around the world continue to participate every year. In 2014, CTF launched the hashtag #EndNF, which can be used to search social media for CTF’s many campaigns, including the “I Know a Fighter” rally cry, introduced in 2015 to capture the remarkable spirit of those living with NF.

In 2014, the Foundation added direct Patient Support to its activities that serves as a point of contact for individuals looking for information and resources.
This year that initiative developed a web-based learning platform that brings NF experts to the broader CTF community, called Ask the Expert. Additionally, the Foundation has established a Patient Engagement Initiative that trains patients on how best to use their experiences to better inform the research process.

TEAM SCIENCE APPROACH

In 2008, CTF launched its first collaborative research project, the NF Preclinical Consortium (NFPC), to create a pipeline of drugs for clinical trials. This collaboration was an important step toward the team science model that CTF exemplifies today. The NFPC made major discoveries with huge impact, including the proof that MEK inhibitors decrease tumor volume in mice. This finding has informed the promising MEK clinical trial of selumetinib currently taking place at the National Institutes of Health. Over 70% of participants in this trial have seen their tumors decrease in size by 20-50%, progress that the NF research field has never seen before! This drug recently received Orphan Drug Status from the FDA and is currently on track to be the first approved drug for neurofibromatosis.

The NFPC concluded in 2013, and its work continued in the NF Therapeutic Consortium (NFTC) until 2016. The 116 preclinical studies performed within the NFPC and NFTC resulted in 16 clinical trials.

Encouraged by this success, CTF developed an innovative research model emphasizing collaboration and cooperation among researchers. The Foundation began an initiative called Synodos, which are multi-year interdisciplinary consortia of scientists, patients, clinicians, technicians, and other experts working in concert.

Synodos for NF2 launched in February of 2014, with the goal of discovering novel therapeutic agents for clinical treatment of NF2. In June of 2016, the first data from the Synodos for NF2 consortia was released to the entire research community via CTF’s partnership with Sage Bionetworks and the creation of the NF Data Portal. Due to the success of Synodos for NF2, Synodos for NF1 was launched in early 2016. This $5 million, multi-year project includes three separate consortia: one to study low-grade gliomas, and two focused on preclinical acceleration. Synodos for Schwannomatosis, CTF’s most recent Synodos consortium, was launched in May of 2017, with a goal of developing effective treatments for schwannomatosis, and a special focus on pain.

On October 2, 2017, the first Synodos Network Meeting was held to bring together the individual groups that make up all Synodos collaborations. Over 70 individuals gathered for this unique opportunity to share research updates and exchange views on Synodos-related matters.

LOOKING TOWARD THE FUTURE

This year, the Foundation celebrates 40 years of driving research, expanding knowledge, and advancing care for the NF community. The early years of the NNFF created a strong foundation upon which CTF has built a research platform that brings researchers, clinicians, patients, funders, and pharmaceutical companies together to collaborate and share data. This pioneering approach is grounded in CTF’s belief that this kind of team approach is the best way to fight rare disease.

As we look toward the future, we are encouraged by our new alliances with pharmaceutical companies, as well as industry partnerships that we are developing. We will keep fueling the drug development pipeline and innovating to remove all roadblocks that keep NF research from moving forward. We will maintain our momentum of engaging and empowering patients to be a part of NF research, awareness efforts, and advocacy.

We’re proud to have led the way in NF research for the past 40 years, and we will continue to do so for the next 40 if needed, so that NF patients can live their lives free of the pain and difficulties that come with neurofibromatosis. One day, we can end NF.

A Conversation with JOAN ENGEL

NF parent and NNFF President 1981-1984

“I connected with Lynne Ann Courtemanche about a year after she started the NNFF. She was so grateful to have someone in New York City with a child affected who was willing and able to help. After the Board met for one of the first planning meetings, I was elected President.

“There was always a very powerful sense that we were doing something important, and that people really needed the organization, because almost everyone would say they had thought initially that they were alone in the world with this disorder. Everybody was hearing, ‘You just have to wait and see.’ And so, to begin to connect with a national organization that had the goal of trying, one day, to cure NF, and to create more successful clinical efforts, was simply wonderful.

“The growth of the Foundation really showed that one person can make a difference. If you ever felt alone, and there was nobody else, well step up to the plate, because look [what can be accomplished]. Truly, when you think that if it hadn’t been for Dr. Rubenstein saying to Lynne, ‘Okay, well if you’re not finding anything, then start something.’ And look where we are today.”

Visit ctf.org/news for a longer conversation with Joan. Joan’s son, Ken Rudd, is currently a member of CTF’s Board of Directors.
The Foundation has a presence across the United States and facilitates local patient support groups, medical symposia, and fundraising events. Learn more about the Children’s Tumor Foundation in your area by visiting www.ctf.org.

**Around the COUNTRY**

Little Heroes of North Georgia

On February 25, 2018, Little Heroes of North Georgia held the sixth annual Little Heroes 5K. This event continues to grow, and this year climbed to 300 registered participants who raised more than $35,000 for the Children’s Tumor Foundation. Local NF Hero Robert Owenby was honored along with other children in the NF community. Endurance athlete Juan Soto won the 5K for the third time—and this year he did so on his lunch break! Thank you to our fearless event chairs Carolanne Owenby and Tara Rogers and the fantastic race committee who continue to put on a spectacular event year after year.

**CUPID’S CHARITY**

**Millions raised for NF research**

February marked the ninth consecutive Cupid’s Undie Run benefiting the Children’s Tumor Foundation. Cupid’s Charity has grown quickly since the first undie run in 2010, when participants raised $10,000. Now, the charity’s annual fundraising is more than $2.4 million, bringing their nine-year total to $16.9 million raised. This Valentine’s-themed party goes to show what a group of fun-loving, magnanimous people can do in the fight to end NF.

In 30 cities across the US, as well as 17 in Australia, Cupid’s Undie Run is a fun and unique way to raise money specifically for NF research. Cupid’s Undie Run is a “brief” 1-mile fun run that takes place in the middle of a big party. Each year, dozens of passionate volunteers help organize Cupid’s Undie Run across the globe and gather with friends and family to dress up, or down, in costumes, tutus, capes and more to celebrate their fundraising efforts.

Our thanks and appreciation go out to Cupid’s Charity and all its volunteers and participants who fundraise for CTF!

**CASINO ROYALE**

In honor of Michele Holbrook, who lives with schwannomatosis, three years ago “Team Amelia” was formed by a dedicated group of Amelia Island, Florida residents to help create awareness and raise funds for CTF. On December 8, 2017, Team Amelia hosted its third annual Casino Royale at the Omni Amelia Island Plantation. More than 200 guests enjoyed an evening of delicious food and beverage and more than $12,000 was raised for NF research.

**I KNOW A FIGHTER 5K**

The Children’s Tumor Foundation I KNOW A FIGHTER 5K TOUR is traveling to 10 major cities this year to raise funds and awareness in the fight to end NF. This family-friendly event will feature a 3.1 mile race and a fun finish line festival. Join the run, form a team, recruit family and friends! Don’t want to run? Help us ensure a terrific race day experience by becoming a volunteer. To learn more and register today: ctf.org/ikaf5k

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Our thanks and appreciation go out to Cupid’s Charity and all its volunteers and participants who fundraise for CTF!
More than 250 people attended the third Annual NF Walk, Boca Raton on Sunday, December 3, 2017, at Florida Atlantic University (FAU). Players from the FAU Owls baseball team joined attendees on a campus 5K walk, while displays were set up to introduce local NF Heroes and their families. Everyone enjoyed field activities, face painting, writing “happy mail” for NF patients, crafting art for CTF headquarters, and reading in a Book Nook honoring the memory of NF Hero Jeane Marie Crouse. Thank you to the Taub family and community sponsors for hosting an informative, interactive, and inspirational day. This year’s event raised more than $66,000!

The Children’s Tumor Foundation’s NF Walk, San Diego had a successful return on Saturday, November 11, 2017 at beautiful Mission Bay De Anza Cove Park. More than 160 walkers participated in the 5K walk to raise funds for NF research and to support our NF Heroes and community. More than $13,000 was raised to support the mission of the Children’s Tumor Foundation. The event featured activities for kids, food, music, and the opportunity to learn about NF Camp!

The annual LA NF Glow Walk was a huge success! The event was held on October 28, 2017 at CBS Studio Center and drew the largest crowd to date of almost 680 participants. Nearly $80,000 was raised for NF research. A special thank you to the LA Walk Committee and all of their friends and family for coming out to this event and making it an evening to remember. Attendees enjoyed a kid’s carnival, a celebrity soccer shootout, costumed characters, food, refreshments, and tons of “glow.” Special thank you to Rocco’s Neighborhood Pizza for their generous support. We are ready for next year so please join us on October 20, 2018 at CBS Studio Center for an even more amazing evening of fun.
We celebrate Mother’s Day with a conversation with philanthropist Carol Harrison and her daughter Becky Irvine, whose son Hunter (age 15) was diagnosed with NF2 in 2010. These faithful and courageous Florida women have participated in numerous CTF events. Together with Hunter’s father, Lance Irvine, who works in the fishing and boating industry, they have used Hunter’s professional fishing tournaments to spread awareness and raise funds for NF research. In 2015, Carol Harrison set up a $250,000 matching gift campaign for Synodos for NF2 which resulted in over $500,000 raised, support that has been instrumental to the success of that project.

CTF: Can you tell us how your family found the Children’s Tumor Foundation?
Carol: My daughter and my grandson are the reasons I got so involved with this organization. When we found out that Hunter had been diagnosed with NF2 back in 2010, it was big. So I decided I would do everything I can. Since the day we found out Hunter has NF, it’s been a long journey.

Becky: Of course when I found out about Hunter I went into panic mode. I was looking for every bit of information I could find on the internet, and one of the first things that came up that was reliable was Children’s Tumor Foundation. Mom and I felt like this was a good resource for us.

CTF: Has becoming involved with the Foundation helped you along this journey?
Carol: Finding this organization has given us so much hope and so much encouragement. When you get the news that your grandson has NF, that’s scarier than anything. You’re going to need every bit of help you can get. I get emotional when I think about it. And having this organization, and knowing it’s fighting for you, looking for a cure—what a gift. I just think CTF is truly a godsend.

CTF: Did you know much about NF2 before Hunter’s diagnosis?
Carol: No, not at all. My daughter, she puts every ounce of energy that she has into learning about NF2. I think she could teach the course! That’s what mothers do, especially Becky. She organizes all the appointments and all the treatments - she keeps everything going.

CTF: Can you tell us a little more about Hunter?
Becky: Hunter is doing really well. He lives his life! He is 15 years old now, and has about 60 fishing trophies. Some time ago he had to have a very serious sinus surgery because of lesions on his sphenoid bone. It was pretty traumatic. But just three days later he competed in a fishing tournament out in the Atlantic Ocean, and it was rough. When he came back into the inlet it was clear that he had a very hard time out there. And then – he won first place! And so many people came up to me afterward and said, “We will never, ever forget that boy and his bravery! Just three days after surgery and he’s knocking this out!” He’s won National Junior Angler, he’s in the IGFA (International Game Fish Association) Hall of Fame. Nothing’s going to stop him, not one thing.

CTF: You have been such faithful supporters of Synodos for NF2. How do you feel about the results coming out of that project?
Becky: Just after my mom’s foundation committed to a $250,000 matching donation for Synodos for NF2, my good friend Tracy Galloway [who serves on CTF’s Board of Directors] called me up one night at about midnight. She said that the data from Synodos has come back and the tumors are shrinking in the mouse models! So yes, we are very, very hopeful – it was so encouraging. It’s all about research. Let’s do it collaboratively and get it done fast. That’s what every mom wants!

CTF: Yes, the Synodos for NF2 data has shown really great results!
Carol: Someday a cure is going to come. We’re just hoping it’s soon. I think it’s my responsibility—as a grandparent of a child affected by NF—to do everything I am capable of doing. You are never too old to help, and I know that CTF needs my support. It’s vital. It’s just so important.

CTF: Thank you for partnering with us now and in the future. Your leadership, commitment, and faith in CTF is greatly appreciated and vital toward our mission to end NF!
Introducing THE NF LEGACY SOCIETY

The NF Legacy Society consists of individuals who have taken the extra initiative to ensure the future of NF research, by including the Children’s Tumor Foundation as a beneficiary in their will or trust, retirement account, or life insurance policy.

Make no mistake about it—the progress that has been made in the fight against NF is because of people like you, who are working to improve the lives of those with NF. It is a legacy of which you can be proud.

To learn more about making a planned gift, please reach out to Melissa Sosa-Longo, VP of Major Gifts, at msosa-longo@ctf.org or 646-738-8549.

The next NF News print newsletter won’t arrive in your mailbox until December, but in the meantime you can find something new almost every day at ctf.org/news. Visit our newsfeed frequently for research updates, industry announcements, events across the country, and inspiring stories from the NF community.

NF News is the official publication of the Children’s Tumor Foundation. All issues are available on our website at www.ctf.org. Please direct any questions or feedback to info@ctf.org.

The Children’s Tumor Foundation is a 501(c)(3) not-for-profit organization dedicated to funding and driving innovative research that will result in effective treatments for the millions of people worldwide living with neurofibromatosis (NF), a term for three distinct disorders: NF1, NF2, and schwannomatosis. NF causes tumors to grow on nerves throughout the body and may lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, and cancer. NF affects 1 in every 3,000 births across all populations equally. There is no cure yet—but the Children’s Tumor Foundation mission of driving research, expanding knowledge, and advancing care for the NF community fosters our vision of one day ending NF. For more information, please visit www.ctf.org.

FOUNDATION STAFF
Annette Bakker, PhD, President and Chief Scientific Officer
Reid Horovitz, Chief Operating and Financial Officer

Research and Medical Programs
Salvatore La Rosa, PhD, Vice President, Research and Development
Vidya Browder, PhD, Basic Science Manager
Kate Keits, Patient Support Coordinator
Pamela Knight, Director, Clinical Program
Patrice Pancza, Research Program Director
Heather Radtke, NF Clinic and Symposium Coordinator
Traceann Rose, Director, Patient Engagement
Sarah Rosenberg, Senior Executive Assistant; Manager of Special Projects & Board Affairs

Development
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Emily Crabtree, Director, Development Operations
Angela Dumadag, Regional Development Manager
Angela Earle, Director, Development Innovations
Channell Hogan, Regional Development Manager
Lolita Jerido, Regional Development Manager
Julie Pantoliano, Senior Manager, Youth Development
Kristine Poirier, Senior Director, Development
Kim Robinson, Regional Development Manager

Major Gifts & Major Events
Melissa Sosa-Longo, Vice President, Major Gifts
Katie Bloom, Director, Major Gifts

Finance and Administration
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Monique Boucher, Gift Processing Manager
Sarah Bourne, Director, Finance
Albert Diaz, Director of IT and Salesforce Administration
Keena Hutchinson, Development and Operations Coordinator
Morgan Kellogg, Gift Processing Assistant
Latisha Maxwell, Gift Processing Coordinator
Carey Milligan, Senior Accounting Manager
David Riordan, Senior Director, Data and Strategy
Connie Sorman, Senior Manager, Volunteer Engagement

Marketing and Communications
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Rebecca Harris, Public Relations Manager
Alissa Marks, Marketing Senior Manager
Susanne Preinfalk, Design Director
Vanessa Younger, Communications Senior Manager

FOUNDED 1987
Children’s Tumor Foundation
Children’s Tumor Foundation Receives High Recognition

These achievements reflect the Foundation’s commitment to being among the best investments in the nonprofit sector, both in terms of its mission and its people.

To learn more about these honors, please visit ctf.org/news.

Charity Navigator gives the Children’s Tumor Foundation its highest rating, 4 stars, for the 9th year in a row, placing CTF in the top 2% of charities in America for best practices, performance efficiency, and fiscal responsibility.

The Nonprofit Times designates the Children’s Tumor Foundation as a 2018 Best Place to Work in its annual ranking of the top 50 charities to work for in America.