Another year and another successful NF Forum event! The NF patients, families, and caregivers at this year’s Forum rated it as among the best. While the event was ideally located in downtown San Francisco and attendees were treated to delicious meals and Ghirardelli chocolate throughout the weekend; we believe what made this Forum so special was that event programming aligned so well with what attendees were interested in learning about.

Over the past several months Dr. Dave Viskochil, Dr. Andrea Gross, Patient Advocates Jessica Samblanet and Maureen Hussey along with Traceann Rose, Director Patient Engagement and Kate Kelts, Patient Support Coordinator at CTF distilled feedback from the NF Community about what they wanted to hear and learn, and organized a dynamic program for the weekend. Inspired by the nearby Golden Gate bridge, the theme for the weekend was ‘Bridging the Gap’ between NF Patients and families and NF Researchers. The NF Forum was held in collaboration with the NF Scientific Conference and the combined gathering enabled NF patients the opportunity to meet experts, discuss current research during the scientific poster session with young investigative researchers, and enjoy continued conversation during a combined dinner of clinicians, scientists and patients. With over 680 attendees the integrated meeting brought the CTF mission full circle; driving research, expanding knowledge, and advancing care for the NF community.

This year we had an extended program starting on Friday afternoon featuring engaging sessions about the The NF2 Landscape and Patient Advocacy in Healthcare and Research. Later that afternoon during the Opening Reception attendees were treated to entertainment from a roving magician while they browsed the patient poster session. This was the second consecutive year that we offer patients and families to get involved and share their NF stories about how they are Bridging the Gap as NF Fighters and Caregivers.

Attendees appreciated having breakout sessions around pediatric and adult manifestations as well as disease specific discussions. They loved having multiple opportunities to get questions answered. The spirit of the weekend was one of support, comrades and learning.

Session for Pediatric NF1 focused around new updates such as the Guidelines for the care of the child with NF1. The New American Academy of Pediatrics (AAP) guidelines for the care of the pediatric patient with NF1 published in 2019 were reviewed, and how they might differ from previous recommendations, was given in this session. NF1 Genetics: Beyond the Basics: A review of the basics of the genetics of NF1 as well as a discussion of why to consider testing, limitations of testing and the exciting research being done on genotypes and phenotypes in NF1. NF1 & School: Bridging the Gap for NF Fighters: this session covered various challenges a child with NF1 might encounter in school. It presented a brief overview of the issues of learning differences, the social-emotional issues that can occur within NF1 and the role of neuropsychiatric testing.
We were thrilled to have a larger than usual Adults with NF (AWNS) attendance at the Forum with a special networking meeting for the group. Sessions covered the **Guidelines for the care of the adult with NF1** that were published in 2018 and were reviewed at the meeting. Both how recommendations for the care of the adults with NF1 may have changed as well as how to work with your primary care doctor. **NF1 Genetics and the Family:** Understanding how the genetics of NF1 can impact family planning decisions. The options for fertility care and the value of genetic counseling for adults with NF1 was discussed. **NF1 & Work: Bridging the Gap as an NF Fighter:** This discussion centered around how medical needs can change related to NF over the course of a lifetime as well as transitioning from pediatric to adult care and the challenges that can come with that.

The NF2 breakout sessions had a large contingent of experts that spent much time answering patient questions both in the room and over the webinar as well as presenting on hot topics for NF2. The **diagnostic criteria for NF2 & Schwannomatosis** were reviewed in 2019, the breakout session provided an in depth review of the diagnostic criteria for NF2 & Schwannomatosis and how it impacts the care of the patient with NF2 or Schwannomatosis. A discussion of **family planning options for individuals living with NF2 or Schwannomatosis.** Covered the value of genetic counseling and the options for genetic testing of children and family members. **NF2 & Hearing Loss: Bridging the Gap:** An overview of the mechanics of hearing loss in NF2, followed by a discussion of life before and after hearing loss including alternative forms of communication and hearing restoration.

There were general sessions that benefitted all attendees. **Over lunch there were round table discussions.** Patients and families joined the NF Clinic Coordinators and Directors for discussion about life with NF. Tables will be designated by the director, coordinator and location.

We heard from two NF Fighters about their journey with NF and how resiliency has impacted them.

**Two very popular, interactive and engaging sessions were the NF and Pain and The Pursuit of Therapy Development Panel discussions.** Pain can play a significant role in the life of the individual with any type of NF and this talk covered how pain impacts quality of life and the latest in pain interventions. **During The Pursuit of Therapy Development Panel** attendees heard from a variety of scientists, researchers, government regulators and medical professionals about the complexities of taking a drug from the laboratory to clinical trials and then through the regulatory approval process. The session was moderated by Dr. Dave Viskochil and questions prepared in advance as well as questions from the audience will be posed to this diverse and talented group. Interactive discussion about clinical trial designs, how patients are working with researchers in endpoint design, how drugs get FDA approval, and patient access to drugs after FDA approval among many other issues in the path to therapy development.
Get Connected! Various groups that are connected to CTF and actively engaged in advancing our mission to END NF set up tables describing their work. Attendees met with and ask questions about what each group does and how to get involved.