Hack4Rare Winning Projects Announced

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New apps and data analyses conceptualized to advance research and enhance collaboration between patients and healthcare providers

Hack4Rare, a global hackathon for rare diseases hosted by the Children's Tumor Foundation (CTF) and MIT Hacking Medicine, today announced the winners of the 2021 virtual event that brought together healthcare startups, researchers, developers, solutions architects, and hackathon enthusiasts for five weeks (June 25-July 30, 2021) to drive scientific and medical innovation and improve the lives of patients living with rare diseases, including: neurofibromatosis (NF), PTEN Hamartoma Tumor Syndrome, RASopathies, and Desmoid Tumors.

Rare diseases represent a research area with high unmet medical need and an opportunity to make a difference in the lives of patients. Throughout the hackathon, CTF, PTEN Foundation, RASopathies Network and Research to the People provided exclusive data sets, mentor support, and input from patients to foster the development of solutions with real-world applications for neurofibromatosis, PTEN Hamartoma Tumor Syndrome, RASopathies, and Desmoid Tumors, respectively.

Solutions ranged from new ways to analyze data; to new patient communication apps; to using gamification as a diagnostic tool and analytical tools for patient portals.

First, second, and third place winners on each track received $1,000, $750, and $500, respectively. The Desmoid Tumor track was a collaborative track focused on a single patient case study and thus no cash prizes were awarded. The winning projects of the 2021 Hack4Rare announced today include:

Neurofibromatosis track;

- **1st place: "Synthetic NF1 MRI Images"**
  Create a biparietal of synthetic MRIs of various tumors seen in the actual clinical scenario of people with NF1. This would address the limitation of limited data sets that have hampered machine and deep learning approaches previously.

- 2nd place: “LetsTalkAboutNF.com”
  A curated podcast series that facilitates discussion around the shared yet unique experiences of the NF community
- 3rd place: “Deep Walked Based Gene Clustering”
  Develop a framework to accurately segment genomic data and tumor samples for neurofibromatosis patients and patients with other rare pediatric cancers.

Expanding on last year’s successful NF Incubator launch, this year, additional funding was made available through the Rare Incubator, with support provided by the Children’s Tumor Foundation, Neurofibromatosis Therapeutic Acceleration Program (NTAP), the Gilbert Family Foundation (GFF) and CFC International to qualifying teams who choose to continue working on their projects for an additional 3-6 months.

The projects qualifying for up to a total of $38.5K in incubation funding included:

- **Synthetic MRI Imaging (NF track)**
- Apptivity (NF track)
  Apptivity makes it easy for patients and doctors to coordinate at-home care, while working around a busy schedule. The app benefits patients, doctors, and insurance providers, and makes it easy for patients to adhere to a complex treatment plan, while simultaneously requiring less time investment from physicians.
- Deep Walked Based Gene Clustering (NF track)
- Let's Talk About NF.com Podcast (NF track)
- “Track Pain” (RASopathies track)

“After the great success of last year's Hack for NF, we expanded the event and invited other rare disease organizations,” said Salvatore La Rosa, Chief Scientific Officer of the Children’s Tumor Foundation. “The addition of PTEN, RASopathies and Research to the People added unique topics and challenges that ultimately resulted in the sharing of underlying data, personal experiences, and common goals. I’m amazed to see such creative applications of ingenuity and I hope these ideas will spark a real breakthrough.”

NF, short for neurofibromatosis, is a genetic disorder that causes tumors to grow on nerves throughout the body. It affects 2.5 million people worldwide and there is currently no cure. There is one approved drug for the treatment of inoperable plexiform neurofibromas, a subset of patients with neurofibromatosis type 1.

RASopathies (Cardio-facio cutaneous CFC, Costello CS, Noonan NS) is a group of rare genetic conditions caused by mutations in genes of the Ras-MAPK signaling pathway (of which neurofibromatosis type 1 is one).

PTEN Hamartoma Tumor Syndrome (PHTS) is a rare genetic condition that causes increased risk for certain cancers, benign growths, and neurodevelopmental conditions.

Desmoid Tumor is a very rare neoplasm that develops from fibroblasts. These tumors do not have the ability to metastasize, but they can cause significant morbidity and mortality by local invasion and they are prone to local recurrence.

More than 300 active participants took part in Hack4Rare from around the world.

“As an NF patient, taking part in the hackathon and working on a treatment solution was really enjoyable and gave me a feeling of empowerment over my NF. With a disease like NF, so much is out of my hands, but it feels great to be able to take an active role to improve my condition and the lives of people with NF,” said Adam Goodkind, a patient living with neurofibromatosis type 2 and a team member on the project Apptivity. “It was genuinely inspiring to see all of the different approaches other competitors are taking to tackle NF. It makes me confident that the future of rare disease research is in good hands.”

“This event brought me together with a variety of thinkers, which helped me find a way to more effectively define and frame what I've been working on for many years: why and how to work with rare disease organizations like ours,” said Lisa Schoyer, Founder and President, RASopathies Network and Hack4Rare NF Mentor. “I connected with a number of people across the world with a shared passion to improve our quality of life.”

This is the third hackathon that the Children's Tumor Foundation has hosted. In September 2019, data scientists, artificial intelligence experts, and engineers gathered at the Google Launchpad in San Francisco, California to ‘hack’ genomic, research, and imaging/clinical data from the NF Data Portal, in order to bring their unique insights and experiences to help accelerate NF medical research. In 2020, the hackathon evolved to a virtual, multi-week competition that brought about solutions to advance research and enhance collaboration between patients and healthcare providers.