Assigning DOI to grants

Keeping track of research outputs

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Children's Tumor Foundation

HRA PRESENTATION

Why assigning DOI to grants?

CHILDREN'S TUMOR FOUNDATION
ENDING NF THROUGH RESEARCH

Publications : Researchers = Grants : Funders

To advance their career researchers:

- Make publications
- Track citations (success metrics)
- Use their publications to find new collaborations
- Look at other publications to advance their own research

To advance their mission funders:

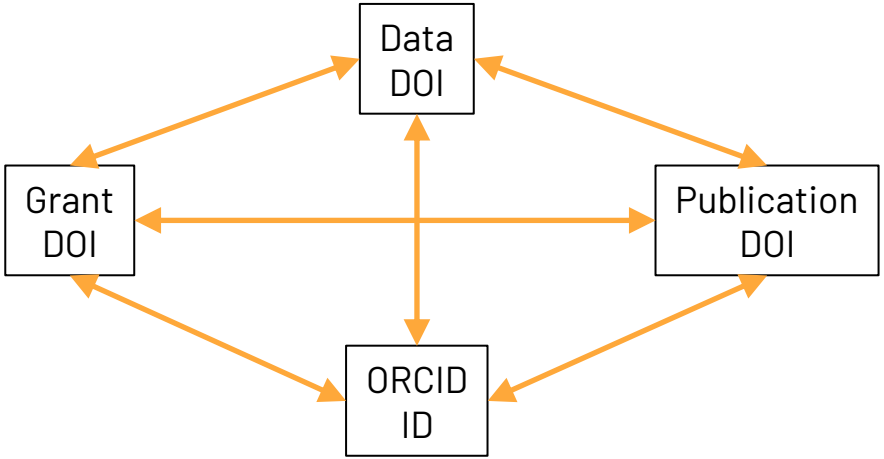
- Make grants
- Track publications out from grants
- Use their grants/grantees to expand the community network
- Look at what other funders funds to avoid duplication and fund unique research

Grant DOIs allow for a more accurate tracking of research outputs

Grants DOI in CTF ecosystem

In 2018 we launched the NF-OSI (NF Open Science Initiative)

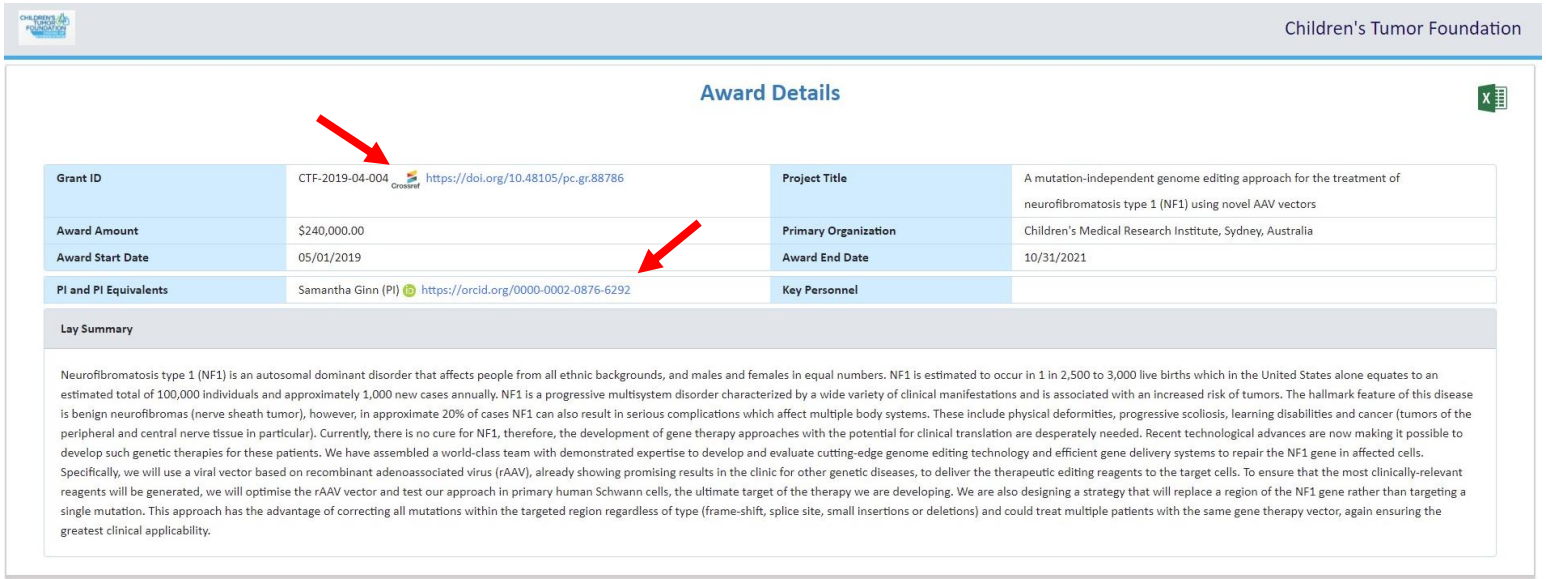
- DOI for grants
- DOI for Data – digital project page on NF Data Portal
- DOI for publications
- ORCID ID for researchers



Benefits

- Avoid lengthy searches to find publications out of grants
  - Reach out to researchers, scavenge for acknowledgments
- Better understanding of research impact
- Better analytics for reporting
- Disambiguation of funding merits - achievements
- Ability to connect multiple types of output together
- Provide a richer experience to all stakeholders
  - Researchers, donors, patients, caregivers, other funders, etc.

Benefits



Children's Tumor Foundation

Award Details

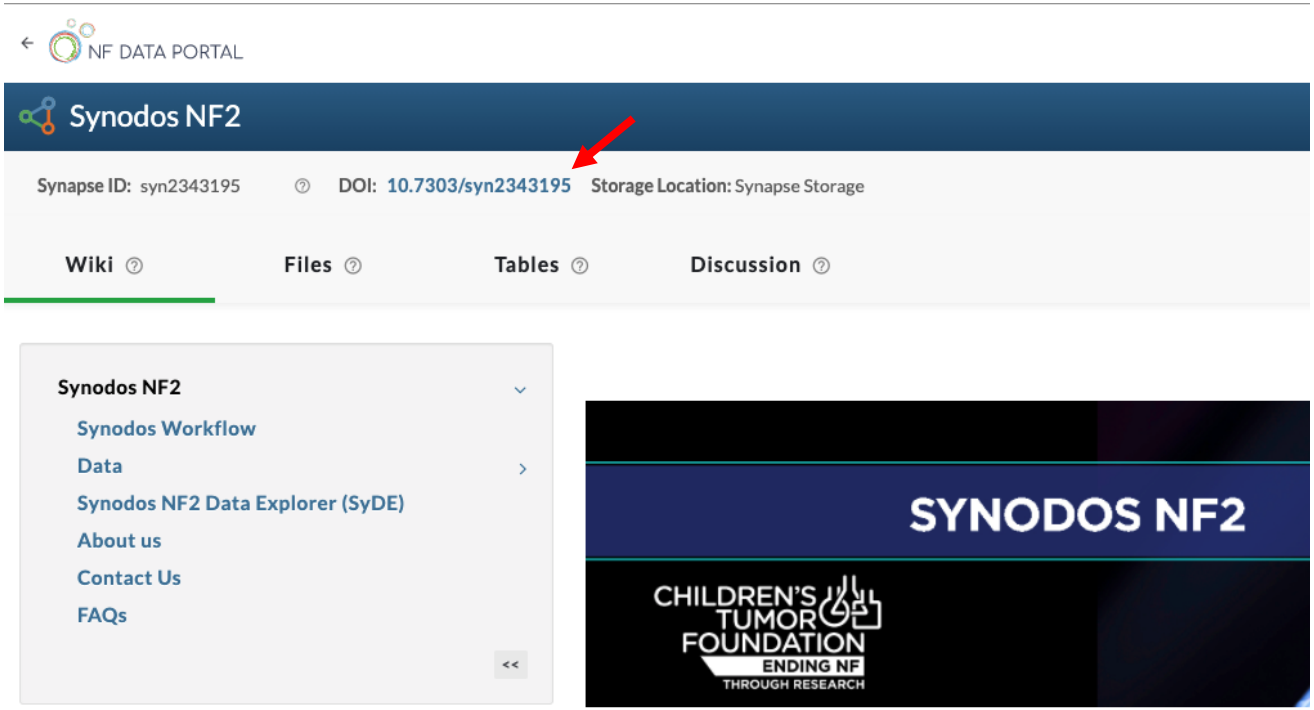
Grant ID	CTF-2019-04-004 https://doi.org/10.48105/pc.gr.88786	**Project Title**	A mutation-independent genome editing approach for the treatment of neurofibromatosis type 1 (NF1) using novel AAV vectors
Award Amount	$240,000.00	**Primary Organization**	Children's Medical Research Institute, Sydney, Australia
Award Start Date	05/01/2019	**Award End Date**	10/31/2021
PI and PI Equivalents	Samantha Ginn (PI) https://orcid.org/0000-0002-0876-6292	**Key Personnel**	

Lay Summary

Neurofibromatosis type 1 (NF1) is an autosomal dominant disorder that affects people from all ethnic backgrounds, and males and females in equal numbers. NF1 is estimated to occur in 1 in 2,500 to 3,000 live births which in the United States alone equates to an estimated total of 100,000 individuals and approximately 1,000 new cases annually. NF1 is a progressive multisystem disorder characterized by a wide variety of clinical manifestations and is associated with an increased risk of tumors. The hallmark feature of this disease is benign neurofibromas (nerve sheath tumor), however, in approximate 20% of cases NF1 can also result in serious complications which affect multiple body systems. These include physical deformities, progressive scoliosis, learning disabilities and cancer (tumors of the peripheral and central nerve tissue in particular). Currently, there is no cure for NF1, therefore, the development of gene therapy approaches with the potential for clinical translation are desperately needed. Recent technological advances are now making it possible to develop such genetic therapies for these patients. We have assembled a world-class team with demonstrated expertise to develop and evaluate cutting-edge genome editing technology and efficient gene delivery systems to repair the NF1 gene in affected cells. Specifically, we will use a viral vector based on recombinant adenoassociated virus (rAAV), already showing promising results in the clinic for other genetic diseases, to deliver the therapeutic editing reagents to the target cells. To ensure that the most clinically-relevant reagents will be generated, we will optimise the rAAV vector and test our approach in primary human Schwann cells, the ultimate target of the therapy we are developing. We are also designing a strategy that will replace a region of the NF1 gene rather than targeting a single mutation. This approach has the advantage of correcting all mutations within the targeted region regardless of type (frame-shift, splice site, small insertions or deletions) and could treat multiple patients with the same gene therapy vector, again ensuring the greatest clinical applicability.

Ability to include more information (links to data DOI, publication DOI, etc.)

Benefits


NF DATA PORTAL
Synodos NF2
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DOI: 10.7303/syn2343195
Storage Location: Synapse Storage
Wiki
Files
Tables
Discussion
Synodos NF2
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