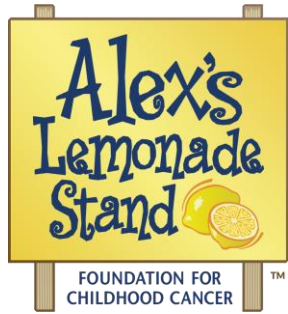


The Importance of Resource Sharing

Anna C. Greene, PhD

Director of Science

Alex's Lemonade Stand Foundation

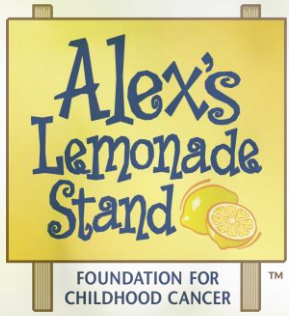


Childhood Cancer

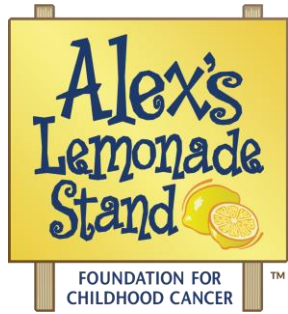
- Childhood cancer is the leading cause of death by disease for children in the US
- 15,590 children are diagnosed in the US each year
 - Globally over 300,000 cases will be diagnosed
- About 85% of children in the US will be cured (~20% will be cured in low and middle income countries)
 - Still, about 1,800 kids die each year in the US
 - There is no cure for the childhood cancer DIPG
- Despite surviving, children will suffer life-long side effects of their cancer treatment.



Alexandra "Alex" Scott (1996-2004)

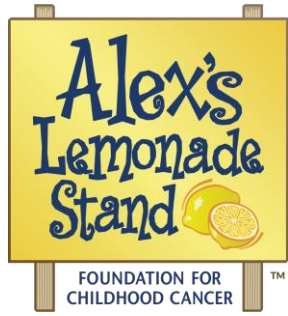


Making Sharing Standard Practice



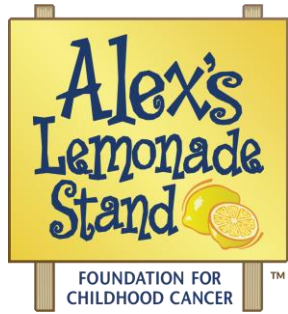
Motivational Quotes

- “If I don’t want to share that with you, I will drag out the time.”
- “There were so many requests, and we shared the mouse model with some other labs.”
- “I would like to share the resources I have but I think it depends on the situation, like if we are competitors, I'm not very willing to share.”



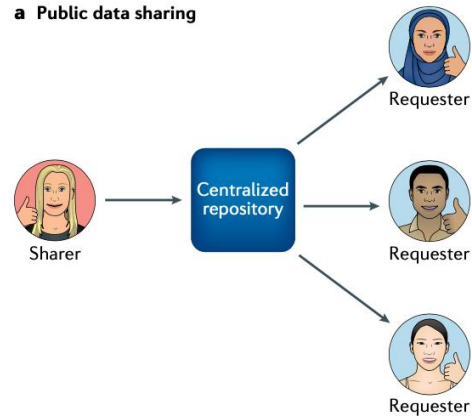
ALSF Perspective

- We're here for the kids. Sharing resources openly will accelerate the pace of discovery and finding cures.
- We want reproducible science, reduction in redundancy and putting research dollars to maximal use.
- Shifting scientific practices toward a culture of sharing will help it to become second nature.
- **Collectively, funders can play a large role in shaping sharing behaviors by requiring sharing.**

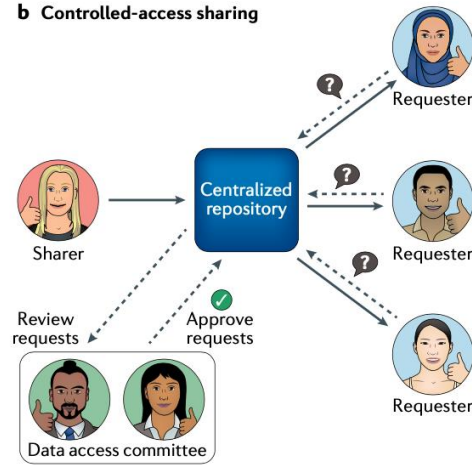


Best Practice: Types of Sharing

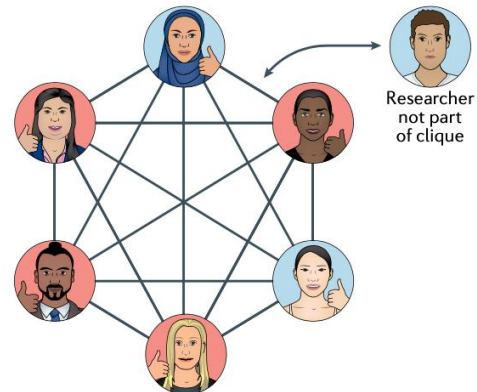
a Public data sharing



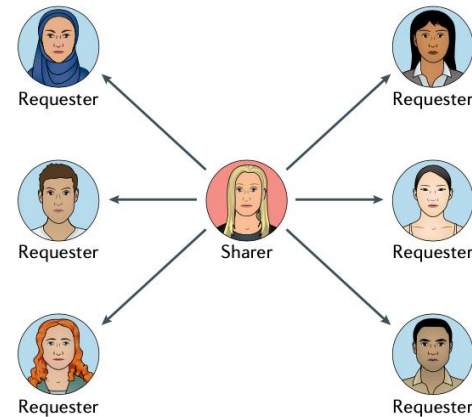
b Controlled-access sharing



c Clique sharing



d Sharing upon request

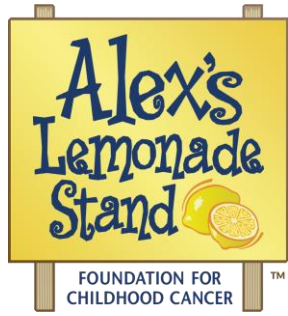




ALSF Resource Sharing Plan

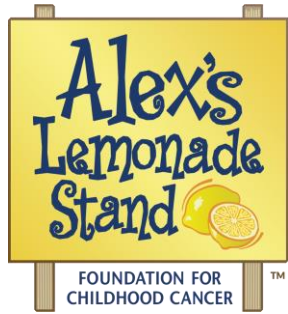
In 2018, required that applicants submit a resource sharing plan as part of their application focused on **planned** and **prior** sharing efforts.

1. What resources will you generate?
 - Data
 - Protocols
 - Materials and Reagents
 - Source Code
2. What repository?
3. Time frame for deposition
4. If no repository, how will they be shared?
5. Prior sharing impact



Sharing Plan Review

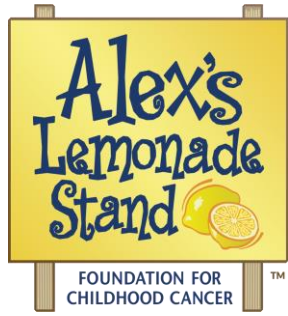
- When reviewing applications, our reviewers score the sharing plan as a review criterion (1-9 scale).
- We encourage budgeting for sharing efforts (Researcher/staff time, IT support etc).
- I review plans internally for those that we plan to award funding. We sometimes ask for updates to the plans. Most comply.
 - We have even not awarded a grant because the researcher refused to share any outputs.



Lessons Learned

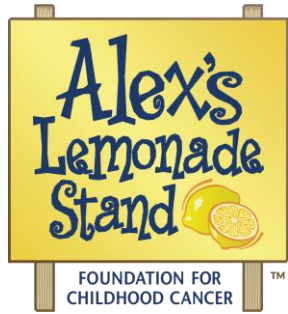
The plans we were seeing initially (and still see to some extent) lack specificity and timelines.

- **I will share by publishing/presenting my results.**
 - Knowledge sharing, not output sharing
- I will share upon request.
 - Puts up a barrier, not unbiased, loss of contact over time with email address
- I will publish research protocols/data/etc on my website.
 - Not persistent (website goes down, PI's move or retire)
- I will adhere to the sharing guidelines required by the NIH.
- I will share, but I need to be involved in the projects with which I am sharing the resource (and approve/disapprove/be included on publications).



Resource Sharing Policy

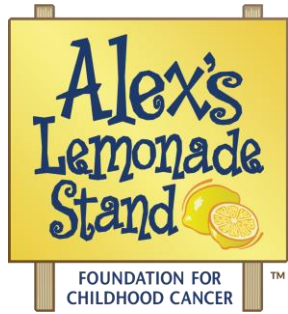
By requiring a sharing plan with no policy attached, **applicants** did not know what our expectations were with regard to sharing, **reviewers** did not know our expectations, and internally, **we** did not know our expectations either.



2021 Resource Sharing Policy

Resource sharing is an **expected** outcome for grants funded by Alex's Lemonade Stand Foundation (ALSF). The goal of the ALSF Resource Sharing Policy is to **enable faster translation of research discoveries into cures for children** with cancer. Resources to be shared encompass **all unique research outputs** developed, including but not limited to: model organisms, cell lines, plasmids, protocols, software, and data. We expect that, where available, **resources will be deposited and archived in standard public repositories.**

- We don't require specific repos, encourage the use of standard field-specific repos.
 - e.g. Addgene for plasmids; SRA for RNA-seq data
- We require sharing by date of publication or within 12 months after the conclusion of funding, whichever comes first.
- The policy applies to all research grants except our summer internship awards and our infrastructure awards.



Compliance

What we are trying:

- We ask for shared resources to be described in progress/final reports.
- We ask progress/final report reviewers to comment on adherence to the sharing plan.
- Because we review for prior sharing behaviors, we hope to reward those who share well and come back to us for more funding.
- We are rolling out a resource sharing portal to make childhood cancer research resources more discoverable.

CCRR Portal Search Add Resource Help Sign in with ORCID ID

Childhood Cancer Research Resources Portal

The Childhood Cancer Research Resources (CCRR) Portal is a platform to enable discovery and sharing of research resources such as datasets, cell lines, PDX models, plasmids, protocols, and more.

Add a Resource
Add a resource to the growing repository of childhood cancer research resources.
[Add Resource](#)

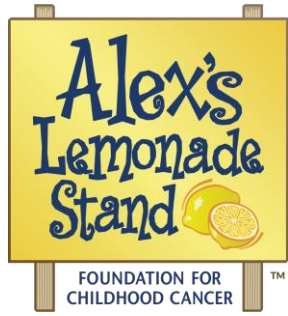
Discover Resources
Search the portal for a variety of pediatric cancer focused resources.
[Search the portal](#)

Reap the benefits of sharing

More citations
Researchers who have data in openly available repositories or deposit plasmids in AddGene are more cited.

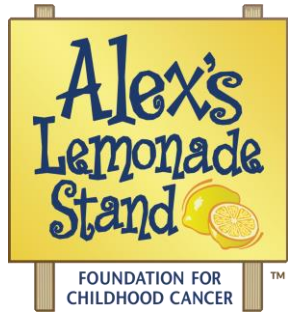
Accelerate Research
Spend less time recreating and managing resources and more time on your research.

New Collaborations
Sharing can lead to new and exciting collaborations, expanding the reach of your research.



Other Lessons Learned

- Leadership buy-in – tied to mission. Doing this for kids.
- We have not received obvious push back from researchers.
- Write sharing requirements into Grant Agreements.
 - We have had to invoke these sharing clauses
 - Institutions have tried to remove sharing clauses from our Grant Agreement
- It does require (FTE) effort to establish and enforce these policies.



Concluding Thoughts

- Funders should have a sharing policy that requires sharing.
 - Require sharing plans and review those plans for impact.
- Fund those who have shared well so that we can positively change the scientific culture of sharing and the way science is done.