



Simons Searchlight Virtual Connect: Insights, Impact, and Collaboration

February 24, 2026

Advancing Research Through Partnership and Shared Purpose

Purpose of Today's Gathering

- Unite Patient Advocacy Groups (PAGs) for a strategic focus on **shared goals**
- Learn how SFARI **research resources** are used by scientists—and where PAGs fit in
- Gain **practical, shareable talking points** to use with researchers and industry partners
- Share **what you need** to better support long-term participation in research
- Explore tools and ideas that help turn community engagement into **real research impact**
- **Feedback:** Please ask questions in the Q&A chatbox throughout the webinar.

Introduction to Simons Foundation Research Resources for Simons Searchlight Communities

Lauren Bauer, Senior Director, SFARI Cohorts and Biorepositories

Casey Lehman, Senior Project Director, Research Match

Overview of Simons Foundation

About the Simons Foundation

The Simons Foundation was established in 1994 by Jim and Marilyn Simons.



Overview of Simons Foundation Autism & Neuroscience Division

Advancing the Frontiers of Research in Mathematics and the Basic Sciences

Grantmaking Divisions

- Autism & Neuroscience
- Mathematics & Physical Sciences
- Life Sciences
- Science, Society & Culture

Flatiron Institute

- Center for Computational Astrophysics
- Center for Computational Biology
- Center for Computational Mathematics
- Center for Computational Neuroscience
- Center for Computational Quantum Physics
- Scientific Computing Core



Kelsey C. Martin, M.D., Ph.D.
Executive Vice President, Autism and Neuroscience

Overview of Simons Foundation Autism Research Initiative (SFARI)

Simons Foundation Autism Research Initiative (SFARI)

Launched in 2006
> 300 SFARI Investigators
Annual Budget - \$100M

Convening

- Workshops & Meetings

Grantmaking

- Individual
- Collaborative
- Early Career
- Institutional

Resources

- Biorepositories
- Cohorts
- Data

Mission Statement:

SFARI's mission is to advance the basic science of autism and related neurodevelopmental disorders.

We fund innovative research, promote collaboration and open science, and develop data, tools and resources that accelerate discovery.

SFARI Research Resources: Simons Searchlight

- Simons Searchlight is a research study, aimed to **establish resources for scientists to study the impact of genes** linked to autism and neurodevelopmental disorders
- **SFARI is the funder and steward of Simons Searchlight data and biospecimens**, including managing access and distribution
- Resources are available to **approved researchers** from verified institutions
- Simons Searchlight participants are **consented under defined protocols** which govern how the data and biospecimens may be shared and used for research purposes

SFARI Research Resources: What's Available for Simons Searchlight

Data:

- Genetic report findings
- Phenotypic data: medical and developmental history, standardized measures (Vineland, Child Behavior Checklist), longitudinal data
- Genetic data: whole genome sequencing (Phase 1 / SVIP)

Biospecimens:

- Whole blood DNA
- Peripheral blood mononuclear cells (PBMCs)
- Induced pluripotent stem cells (iPSCs)
- Fibroblasts (Phase 1 / SVIP)
- Coming soon: plasma

Research Match: A service that allows researchers to recontact participants in SFARI cohorts for new studies. To date, nearly **2,000** Simons Searchlight families have joined studies through Research Match.

SFARI Research Resources: What's Available for Simons Searchlight

PBMCs:

- Newly available for request by researchers for the purposes of iPSC creation
- Limited, non-renewable resource – rigorous review of researcher's planned reprogramming methods and quality control assays prior to approval (ideally using same or similar methods to SFARI generated lines)
- PBMCs already in progress for iPSC generation are not available for distribution concurrently
- SFARI will evaluate any generated iPSCs for import, banking, and expansion for distribution

iPSCs:

- SFARI has generated 300 iPSCs (200 probands + 100 familial controls) through The New York Stem Cell Foundation (NYSCF) (all lines are either completed and available, in progress, or selected)
- iPSCs are created through an automated, standardized process and go through the same quality control metrics
- **Stay tuned!** Continuation of iPSC generation through a formal Request for Nomination process by researchers - up to 60 iPSC lines per year; launching in mid-2026

SFARI Base: A Centralized Repository for Data and Biospecimen Access

- Controlled access to request all SFARI data and biospecimens
- Browse available data and biospecimens without logging in
- Scientific approval of all requests
- Tracks compliance requirements, such as IRB documentation or consent restrictions
- Bi-annual project updates and 3-year renewals for access

The screenshot shows the SFARI Base website. At the top left is the SIM NS FOUNDATION logo. The main heading is "SFARI Base". Below it, a paragraph states: "SFARI Base serves as a centralized repository for autism and autism-related research data and biospecimens, along with an online portal facilitating research recruitment requests." There are two buttons: "Available Resources" and "Learn More". On the right, there is a login form with fields for "Email" and "Password", a "Log In" button, and links for "Forgot your password?" and "Don't have an account? Register".

SFARI Base is supported by the Simons Foundation Autism Research Initiative (SFARI) and it contains data from the following cohorts:

Cohort	Participants Enrolled	Genetic Conditions Studied	Publications
Simons Searchlight Individuals with a genetic diagnosis associated with one of the 185 conditions linked to ASD, and their family members	5,600+	185+	85+
Simons Simplex Collection (SSC) Individuals with ASD with a clinical diagnosis, and their family members from simplex families	2,600 families	All families	200+

Simons Searchlight data types: Phenotypic, WES, WGS, Whole Blood DNA, PBMCs, LCLs, iPSCs, Imaging, SNP array.

Simons Simplex Collection (SSC) data types: Phenotypic, WES, WGS, SNP array, Whole Blood DNA, Saliva DNA, LCLs, Fibroblasts, iPSCs, PBMCs.

SFARI Base: Simons Searchlight Datasets

- Filter for Simons Searchlight-specific datasets
- Expand for dataset descriptions, links to Researcher Welcome Packet, data dictionary, and public release notes

SIM NS FOUNDATION Log In

Type: Cohorts: Dataset Origin: Clear filters

Simons Foundation Datasets **[S]**

Dataset/Accession ID	Type	Name	Cohort
DS0000032 [S]	Phenotype Data	Simons Searchlight Dataset	Simons Searchlight
		Phase 2 of the Simons Searchlight (formerly Simons VIP) study extended remote online behavioral assessment and telephone interviews to individuals with defined single gene mutations associated with ASD and neurodevelopmental disorders, and their parents and siblings. The complete list of VIP genes of interest can be found on SFARI.org. Additional genetic findings beyond the primary genetic change are not exclusion criteria.	Simons Variation in Individuals Project Welcome Packet
		More detailed information about Simons Searchlight is available in the Researcher Welcome Packet.	

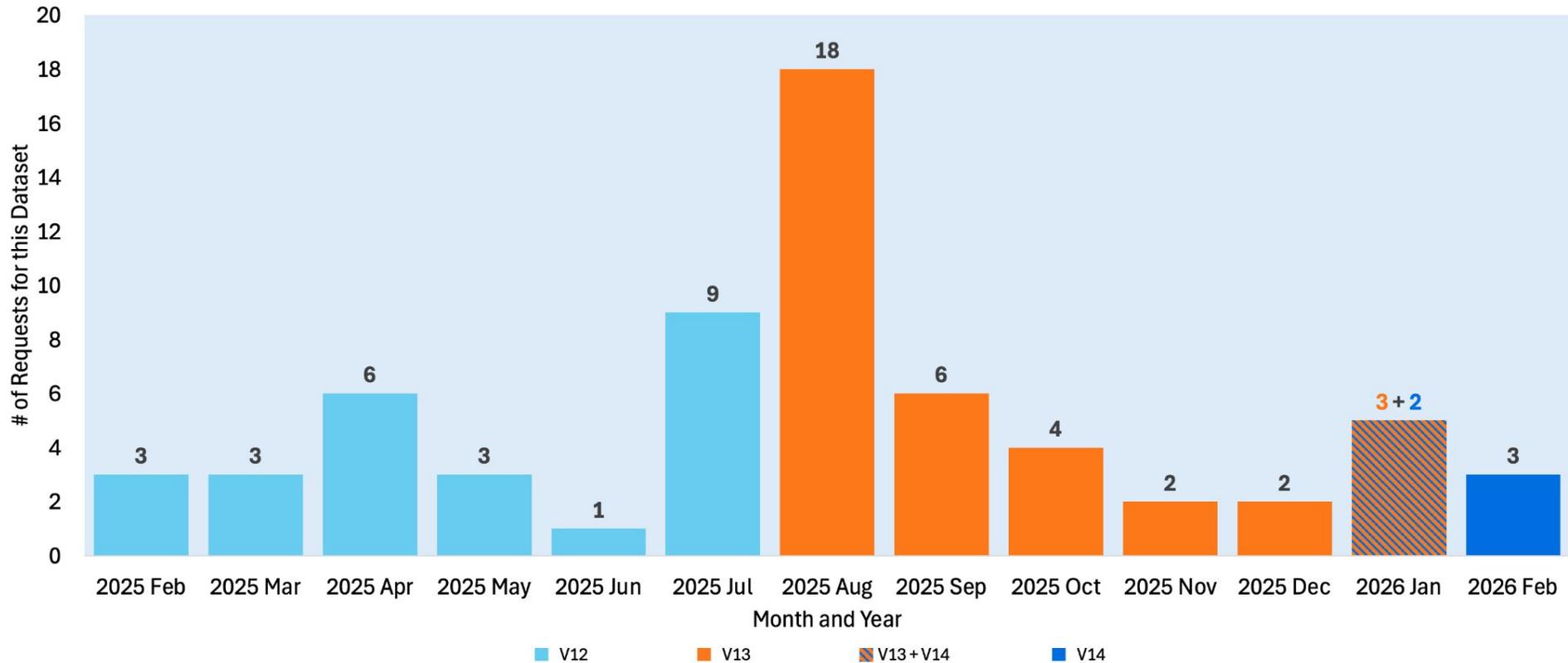
Simons Searchlight Resources: Access by Researchers

- Requests for the updated Searchlight datasets: **40 new requests for v13 and v14** in 2025/2026
- iPSC vials approved for distribution in 2025: **319 vials**
- iPSC vials approved for distribution since 2020: **1227 vials**
- Over **1300+ SFARI Base users** annually
- Over **100 new institutions** in 2025

Simons Searchlight Resources: Access by Researchers

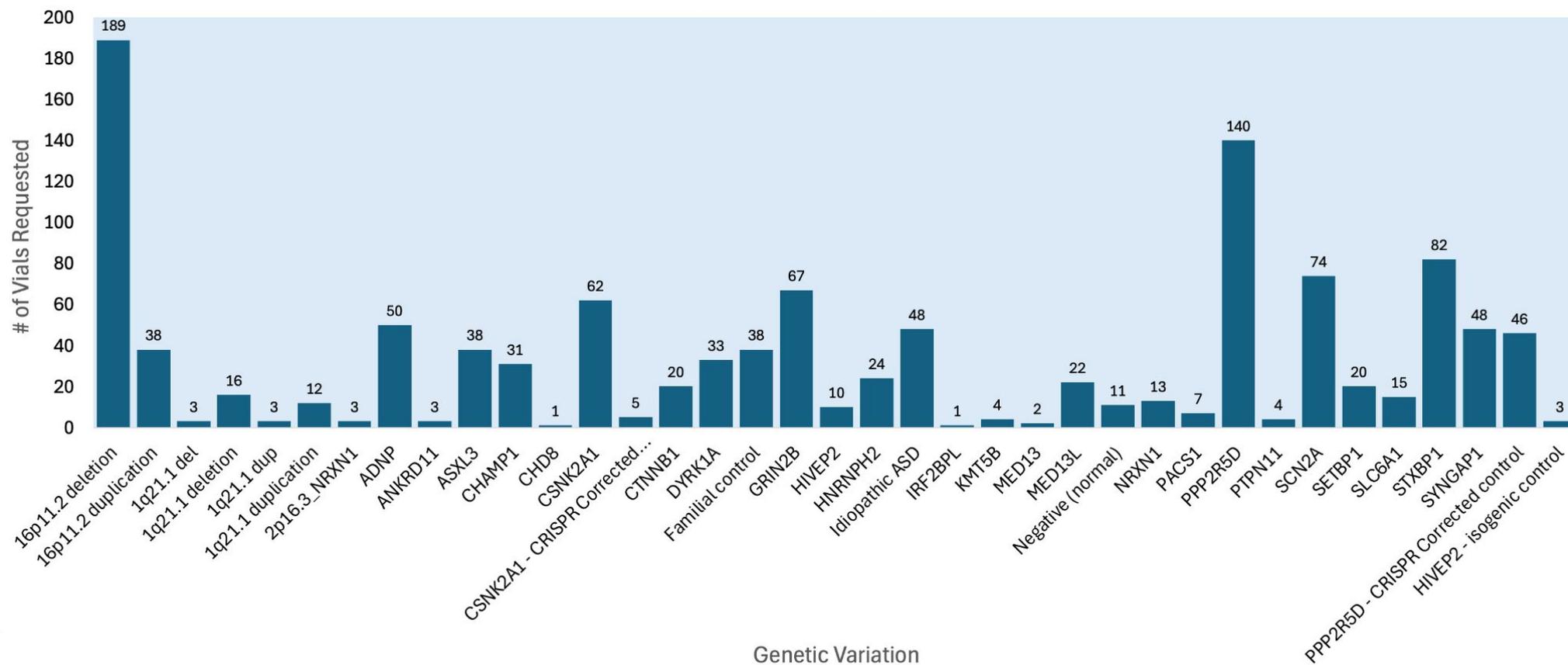
Total number of Requests for the Searchlight Phenotype Dataset

February 1st, 2025 - February 20th, 2026



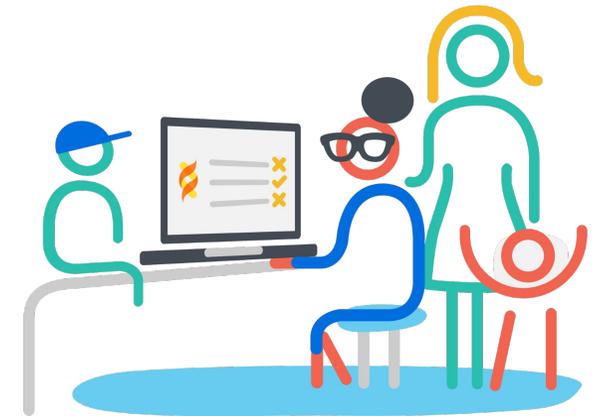
Simons Searchlight Resources: Access by Researchers

Total Number of iPSC Vials Requested Since 2020 Organized by Genetics



Research Match Deep Dive: What It Is

- Simons Searchlight Research Match (RM) **launched in 2021**
- Simons Searchlight RM invites Simons Searchlight participants to participate in **new** research that is **not** part of the main Simons Searchlight study
- In kind support from SFARI means no cost to the researcher for access to the RM platform for most projects
- Invited over **3,823 families**, over **1,976** of whom have responded to nearly **25 RM projects**



Research Match Deep Dive: What It Is

- **Two types of Research Match studies**
 - **“Handoff” studies** - researchers need to see participants in clinic, or contact them to complete some kind of specific remote task, such as an interview
 - **Online survey studies** - surveys are built within the Research Match platform, completed all within the same browser window
- **Participants always have a choice!**
 - **“Handoff” studies** - choose to share information with the new study team to schedule a visit in-clinic, interview, etc.
 - **Online survey studies** - Complete surveys online, with no identifiers shared with the study team.



Research Match Deep Dive: What It Is

- After the study is over:
 - Researchers may be asked to help Simons Searchlight **communicate the results** back to participants and the Simons Searchlight community.
 - Researchers agree to **share data back** with Simons Searchlight for distribution on SFARI Base after 12 months or publication, whichever comes first
- Goal of Research Match is to **catalyze connections** so that researchers with good ideas can be matched with participants who want to join research
- Capitalize on the strengths of Simons Searchlight to move the field forward



Research Match Deep Dive: How It Works

- Receive email invitations to studies for which you and/or your dependent may be eligible
- Participant reads the information and decides whether to share information and/or join the study



The screenshot shows an email invitation from Simons Searchlight. The header is purple with the Simons Searchlight logo and the text 'Research Match'. The main content is white with a purple border. It features a bold heading 'New Research Study Opportunity', followed by the study name 'Examining the Challenges of Adolescents and Young Adults with Autism'. The email is addressed to 'Casey' and invites participation in a new research study. A dashed line separates the invitation from the 'Study Information' section, which includes a checkmark icon and the heading 'What is involved?'. Below this, two bullet points describe the study requirements: completing interviews and questionnaires, and attending 4 study visits (remotely) over a year.

SIMONS SEARCHLIGHT | Research Match

New Research Study Opportunity

Study Name: Examining the Challenges of Adolescents and Young Adults with Autism

Dear Casey,

You are invited to participate in a new research study led by [Researcher] at [Institution].

Study Information

✓ **What is involved?**

- You and your child will be asked to complete interviews and questionnaires.
- There are 4 study visits (visits can be done remotely), each one year apart.

Research Match Deep Dive: Highlights

- Simons Searchlight communications team collaborates with the study researcher to **highlight published research**
- These summaries are written in **lay-friendly language** and placed on the Simons Searchlight website
- Links to published articles are also included



RESEARCH MATCH
Dr. Thomas Frazier's Webcam and AI Study Drives Discovery

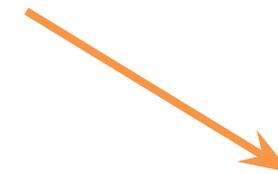
Erica Jones | September 8, 2023 SHARE [f](#) [x](#) [in](#) [e](#)

“ I just want to encourage people to take time out of their day to communicate with researchers and let us know how we can help them make the research more applicable and accessible. But please participate, participate, participate!

Thomas Frazier, Ph.D.

Meet Dr. Thomas Frazier, Professor of Psychology at John Carroll University and a Simons Searchlight researcher working on an exciting study using webcams and AI to understand how people with rare genetic conditions think and interact. A big thank you to Simons Searchlight participants for taking part in his research through our [Research Match program](#) – your contribution is driving insightful discoveries. Dr. Frazier's research study was supported in part by the [Simons Foundation Autism Research Initiative](#).

Learn more about Dr. Frazier and his research!



Scan to check out the article!

Research Match Deep Dive: Highlights

- Researcher Somer Bishop at the University of California San Francisco recruited Simons Searchlight participants for a study developing a new measure of social and communication ability
- Parents of children under age 18 who had completed Simons Searchlight's background history form were invited to do the online surveys
- All gene groups were eligible

RESEARCH **Open Access**



The Developmental Assessment of Social Communication Ability (DASCA): initial creation and psychometric description

Aaron J. Kaat¹, Audrey Thurm², Cristan Farmer², Shuting Zheng³, Sheila Ghods⁴, Stelios Georgiades⁵, Stephen Kanne⁶, Shrikanth Narayanan⁷ and Somer L. Bishop^{4*}

About the study: *In this study, the researchers created the Developmental Assessment of Social Communication Ability (DASCA), a new survey developed as a clinical outcome tool for monitoring a person's social and communication changes in response to treatment. Measures of change over time are important for clinical trials*

Research Match Deep Dive: Common FAQs

- **How can I hear about Research Match studies?**
 - We will reach out to you with an email invitation, at the same email you used to register for Simons Searchlight, if you are eligible for a Research Match study
- **How can I get my gene included in a Research Match study?**
 - Researchers apply to Research Match with their research questions and eligibility and are approved to contact those individuals only
 - Encourage researchers working with your PAG to apply to Research Match!

SFARI Resources & Research Match Q&A

- **Open Zoom poll questions: SFARI Resources**
 - What would help researchers, clinicians, and industry partners better discover and understand SFARI and Simons Searchlight resources?
- **Open Zoom poll questions: Research Match**
 - What support would help you encourage researchers to use Research Match?



From Resources to Impact: Supporting Long-Term Engagement Together

Astrid Rasmussen, Senior Program Manager, Simons Searchlight

Erica Jones, Outreach Manager, Simons Searchlight

Supporting Long-Term Engagement Together

Goals for Discussion

- **Understanding longitudinal research** the importance of sustained participation
- **Role of patient advocacy groups (PAGs)** in research
- PAGs can communicate the value of Simons Searchlight to **researchers, clinicians, and industry**
- Identifying tools, resources, and data to **strengthen those conversations**
- **Additional and better support** from Simons Searchlight to your community



From Resources to Impact: Interactive Discussion

Discussion topic 1

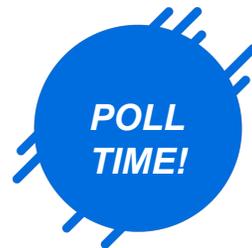
Why is it important for families to continue their participation in Simons Searchlight over time?



From Resources to Impact: Interactive Discussion

Discussion topic 2

Where do you see your patient advocacy group (PAG) playing the strongest role in advancing research?



From Resources to Impact: Interactive Discussion

Discussion topic 3

When discussing the value of Simons Searchlight with researchers, clinicians, or industry partners, what information or tools would be most helpful to you?



From Resources to Impact: Interactive Discussion

Discussion topic 4

What is one thing Simons Searchlight could do to better support your PAG in advancing research?



Thank You for Joining Today!

Your partnership and engagement means so much.

Please share any final ideas, questions, comments or feedback with Erica Jones at Erica.Jones@childrens.harvard.edu