



Welcome to the [Data for the Common Good](#) (D4CG) quarterly newsletter! Read on for announcements from D4CG headquarters, Pediatric Cancer Data Commons updates, highlights from recent meetings, and more. Past quarterly newsletters are [archived on our website](#). Please don't hesitate to [reach out with suggestions and requests](#).

Join us for a D4CG webinar



Empowering epilepsy research through international data sharing

Building a monogenic epilepsy data commons

November is National Epilepsy Awareness Month! Join us on November 19 to learn about how D4CG, with support from the Chan Zuckerberg Initiative, is building an international epilepsy data commons. You'll hear from epilepsy and EEG experts about their research focuses and how the epilepsy commons will help advance treatment and cures for monogenic epilepsies.

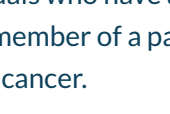
Empowering epilepsy research through international data sharing: building a monogenic epilepsy data commons

Tuesday, November 19, 2024

12:00-2:00pm CT

[Register](#)

Call for Nominations



Pediatric Cancer Data Commons Lived Experience Advisory Panel

D4CG is assembling a **Lived Experience Advisory Panel (LEAP)** composed of pediatric cancer patient advocates who will provide strategic and operational guidance for the Pediatric Cancer Data Commons. We are seeking nominations for patient advocates to join the LEAP: individuals who have a personal experience with pediatric cancer, either as a patient or family member of a patient who has been treated, who are passionate about the study of pediatric cancer.

Please nominate yourself or someone else by sending their name and contact information to PCDC Program Director [Kat Bouzein](#). You may also reach out to Kat with any questions about the LEAP. Thank you!

Upcoming Conferences

We're looking forward to these meetings in the next several months. If you're attending, we hope to see you there! If you'd like to schedule a meeting with D4CG at any of these conferences, please reach out to [Kat Bouzein](#).

- ◆ [CZI Science in Society Annual Meeting](#), October 17-20 in San Jose, CA
- ◆ [SIOP Annual Congress](#), October 17-20 in Honolulu, HI*
- ◆ [International Symposium on Hodgkin Lymphoma \(ISHL13\)](#), October 26-28 in Cologne, Germany
- ◆ [AMIA Annual Symposium](#), November 9-13 in San Francisco, CA*
- ◆ [Annual Conference of the Oncofertility Consortium](#), November 11-13 in Detroit, MI
- ◆ [CTOS Annual Meeting](#), November 14-17 in San Diego, CA
- ◆ [EpSSG Winter Meeting](#), December 4-6 in Paris, France
- ◆ [ASH Annual Meeting](#), December 7-10 in San Diego, CA

*We hope to see you at our D4CG booths and poster presentations at SIOP and AMIA!

D4CG Announcements

Bringing a D4CG workshop to India

We are excited to have the opportunity to build and strengthen D4CG collaborations in India through a new workshop in February 2025. Thanks to support from a University of Chicago [Provost's Global Faculty Award](#), the **India Data Sharing and Harmonization workshop (DaSH)** will bring together clinicians and researchers throughout India at the [University of Chicago Center in Delhi](#) to work toward bringing local solutions to global problems. Our goals for this workshop include:

- to build local capacity in technical data modeling and aggregation, team data science, clinical data standards, data governance processes, and involvement in international clinical research initiatives;
- to increase collaboration between D4CG, the [Indian Pediatric Hematology Oncology Group](#), and Indian institutions; and
- to increase Indian representation in PCDC-affiliated consortia and encourage data sharing and contribution to the commons.

Prior to the workshop, members of the D4CG team will visit Tata Memorial Hospital in Mumbai and Rajiv Gandhi Cancer Center Institute in Delhi. We look forward to this opportunity to meet our colleagues and build new collaborations! Any questions may be directed to D4CG Sr. Project Manager [Thivashnee Sharma](#).

D4CG and Team Bright Side begin survivorship project

D4CG and [Team Bright Side](#) have partnered on a new survivorship initiative, **Bright Side Navigator**, that aims to address the challenges for childhood cancer survivors in their follow-up care throughout their lives. The goal of this project is ultimately to create a widely-available ecosystem for patients, providers, and researchers to access a wide range of data and recommendations for care for survivors of cancer. In this ecosystem, cancer survivors will have continuous access to their treatment and follow-up data, with the ability to share data on demand with clinicians. In a later phase of the project, a de-identified version of the data could be added to a long-term follow-up data commons to enable researchers greater access to these valuable data.

The first phase of the Bright Side Navigator project is beginning this autumn and consists of a qualitative study to better understand the experiences of pediatric cancer survivors, which will include interviews with patients and families. Anyone interested in participating in the study may contact D4CG Research Coordinator [Zari Henry](#).

Hyundai award funds new work leveraging AI for survivorship

We are honored to be the recipients of a [Hyundai Hope on Wheels](#) Survivorship Collaboration Award which will fund a new three-year project focused on using electronic health records (EHR) and natural language processing (NLP) tools to address survivorship needs.

RESILIENT (Record Extraction and Survivorship Insights Leveraging Integrated EHR and NLP Technologies) will include three phases. First, we will develop infrastructure to transfer EHR data of childhood cancer survivors via patient access APIs—the same connections used by Epic's MyChart and other patient-facing platforms. Next, in collaboration with Dr. Guergana Savova, we will use the text processing tool [DeepPhe](#) to extract and summarize treatment exposure data like chemotherapy, radiation, and surgery from free-text notes in the EHR. Finally, we will make the processed data available in a structured format for use by other platforms, such as research registries and digital tools for survivors like [Passport for Care](#). Through the RESILIENT project, we have the opportunity to reduce the need for manual data entry into these important downstream platforms and improve clinical care and research for pediatric cancer survivors.

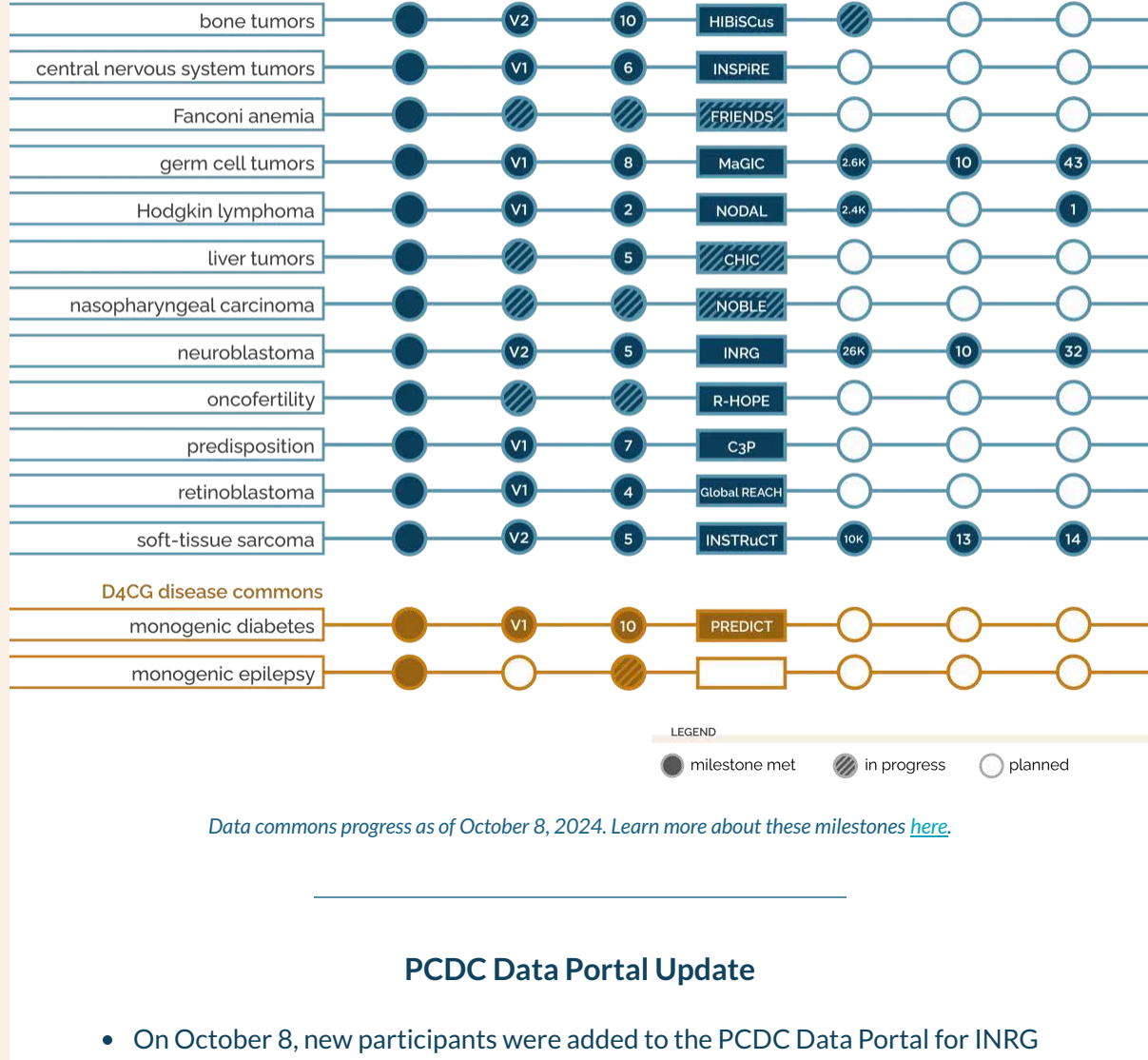
Fall conference highlights

D4CG is in the midst of our busiest autumn of conferences and in-person meetings yet! Here are some highlights from September:

- Sam Volchenboum and [INRG](#) founder Sue Cohn were honored to visit the White House for a meeting convening the winners of the Office of Science and Technology Policy (OSTP) [Open Science Recognition Challenge](#).
- Sam Volchenboum participated in the [Open Research Community Accelerator \(ORCA\)](#) Open Science Dynamic Convergence Workshop.
- At the Children's Oncology Group Fall Meeting, Kirk Wyatt hosted the Informatics session and gave D4CG updates at the AML (Steering and General) and Epidemiology sessions. Suzi Birz presented at the Industry Relations Committee Symposium. PCDC consortia [HIBISCUS](#) and [NODAL](#) met, and we had a rare in-person meeting with our [Scientific Advisory Committee](#) co-chairs!
- At the [Fanconi Cancer Foundation](#) Scientific Symposium, the Fanconi anemia consortium [FRIENDS](#) presented a poster and had a ceremonial MOU-signing celebration and planning committee meeting.
- Sam Volchenboum gave the keynote presentation at the [Leukemia & Lymphoma Society Dare to Dream](#) Forum.
- Luca Graglia presented about GEARBOX at the [NCI Informatics Technology for Cancer Research \(ITCR\)](#) annual meeting.
- Sam Volchenboum gave a talk at the [EHA-SFPM Precision Medicine Meeting](#), a joint meeting bridging between functional and genomic precision medicine.
- We attended the [Hyundai Hope on Wheels Survivorship Summit](#) which will fund our RESILIENT project, discussed above.

Data Commons Progress

Bringing data together for the Pediatric Cancer Data Commons and our other D4CG data commons is the work of many dedicated groups of researchers, clinicians, statisticians, and other experts. This tracker shows each group's progress on the journey of establishing governance, harmonizing data, and publishing research.



Data commons progress as of October 8, 2024. Learn more about these milestones [here](#).

PCDC Data Portal Update

- On October 8, new participants were added to the PCDC Data Portal for INRG (neuroblastoma), INTERACT (AML), and MaGIC (germ cell tumors). With this update, the portal now totals 45,117 participants.
- The details of all [data release updates](#) and [software updates](#) for the portal are available on our documentation website.

PCDC Advisory Group Update

- The [Scientific Advisory Committee](#) met in September. The topics of discussion included EHR data extraction and patient-initiated data exchange.
- As discussed above, we anticipate launching a new Lived Experience Advisory Panel (LEAP) in November. This new group is being developed based on discussion at the Patient and Parent Involvement Workshop we held in June. We are currently seeking nominations for members, and we look forward to sharing more details after the group's inaugural meeting.

We are grateful to our [sponsors and donors](#) for making our work possible.