

Required information for family registration

2022 Speak Now for Kids Family Advocacy Day



Hospital Staff Information

Contact information for primary, government relations, and public relations contacts:

Name and Title
Hospital, City and State
Office and Cell Phone
Email Address

What policy issues are you planning to address with your members of Congress?

Family Participation

How many family members participate in Family Advocacy Day (includes appearing in social media, meeting with lawmakers and/or speaking with the media)?

Please list the names of family members who will participate in Family Advocacy Day.

Media Questions

Does the patient family have experience doing interviews with the following (check all that apply)?

Radio / Television / Print / No Experience

Does the patient family have accounts on social media they would like CHA to tag/link in association with Family Advocacy Day (check all that apply)?

Facebook / Blogs / Instagram / YouTube / Twitter / No accounts

Please provide any *patient family* social media account information that will be used to promote the family's participation in Family Advocacy Day (e.g., hashtags, blog URLs, Facebook accounts, Instagram and Twitter handles).

Are there serious privacy concerns associated with the child patient(s) or other attendees (e.g., the child patient is a foster child) that would prohibit their image being captured in photos or video?

A component of Family Advocacy Day is outreach to news media with patient family stories. CHA typically pitches family stories to national media outlets and helps support some hospitals with their local media outreach. Would your family be open to being considered for national media pitches?

Parent/Guardian Information

Parent/Guardian Contact Information (for parent or guardian coordinating the family's participation in Family Advocacy Day)

Name
Address
City, State, Zip Code
Primary Phone
Email Address

Is the parent/guardian comfortable conducting interviews in English?

Second Parent/Guardian Contact Information (if they will be participating in Family Advocacy Day)

Name
Email Address

Children Details

For each patient and attending siblings:

Gender
Birth Date
T-shirt Size

Child Patient Profile

Patient's formal name and hospital confirmation

Patient is comfortable participating in interviews in English:

Yes
No, patient is not conformable being interviewed
No, patient is nonverbal or has limited verbal skills

Patient ethnicity (check all that apply)

American Indian or Alaska Native
Asian/Pacific Islander
Black/African American
Hispanic
White
Other

The following fields will be used to craft the child patient’s digital trading card. Please limit answers to 20 words or less.

- Name (as displayed on trading card)
- Primary Diagnoses
- Secondary Diagnoses
- Age at diagnosis
- Number of pediatric specialists
- Favorite activity
- Insurance Status
 - Medicaid / CHIP / TRICARE / Private Coverage / Other
- My children’s hospital is important to me because they _____

Please describe when you first knew your child would have the special care needs that brought you to your children’s hospital. This could be the time of diagnosis, the time of prenatal testing, when your child's behavior shifted, or whatever else is a meaningful change point for your family.

What was the immediate impact after diagnosis on your child and your family?

What treatments or care have been necessary at the children’s hospital? Please walk us through how this care has shifted after their diagnosis. What treatments are ongoing?

Patient’s current medical status and how they are doing now

Has the COVID-19 pandemic affect your child’s quality of life?

What, if any, difficulties have you experienced as a result of insurance issues?

Does your child travel across state lines to get needed care, either currently or in the past?

What is the farthest distance your child has had to travel for care?

Please check all options that currently apply or have applied in the past.

- Patient requires care from multiple specialists.
- Patient sees multiple specialists in various locations.
- Patient sees specialists in one coordinated setting/medical home.
- Patient has experienced wait times to be seen by a pediatric specialist. If so, how long were wait times?

Digital Trading Card Photograph

Upload a high resolution digital photograph of the children’s hospital patient. Photographs must be .jpg format and 300 dpi resolution or higher. If more than one member in the family is a children’s hospital patient, at least one photo per patient is required.

Following completion of the survey, CHA will provide you and your family with pre-filled personal health information and publicity release forms to be signed digitally. Signed forms are required before CHA can create child patient trading cards and share patient stories.