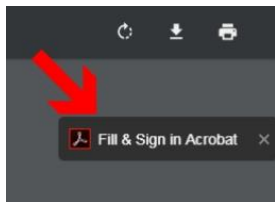


Instructions: Please download this PDF, use this button, top right:



or, click on the “Fill+Sign in Acrobat”



Open it on your computer, fill it in, and then save it as filled.

Next, email it as an attachment to dina@caresfoundation.org.

PATIENT SURVEY

By completing this survey, you are giving consent for CARES Foundation to review your responses for the purposes of continuing evaluation of the CARES Foundation-designated center. This information will not be shared with anyone outside of this Center or the CARES Foundation.

Please select Center where you received care

- ☐ Children’s Hospital Los Angeles/USC/Cedars Sinai
- ☐ Cook Children’s Health Care System
- ☐ Cohen Children’s Medical Center at Northwell Health
- ☐ New York-Presbyterian/Weill Cornell Medical Center
- ☐ Riley Hospital for Children at Indiana University Health
- ☐ Rutgers-RWJMS, Child Health Center of New Jersey
- ☐ Seattle Children’s Hospital/University of Washington
- ☐ UT Southwestern Medical Center/Children’s Medical Center Dallas

Individual completing survey:

- ☐ Patient
- ☐ Parent/Caregiver

Patient information

Gender: ☐ Female ☐ Male ☐ Other

CAH Type:

☐ Non-Classical CAH ☐ Classical CAH ☐ Unknown ☐ Other

Age: Infant (under 1 year) ☐ Child (1-18 years) ☐ Adult (over 18 years) ☐

State you live in _____

☐ New patient

☐ Existing patient

Date of First Consult: _____

How did you hear about the center? _____

Was your visit related to a surgical procedure?

☐ yes ☐ no

Which doctor did you see at this visit?

☐ Pediatric Endocrinologist

☐ Adult Endocrinologist

☐ Reproductive Endocrinologist

☐ Other _____

Care Coordination/Transition of Care

Do you know who the care coordinator is? ☐ yes ☐ no

Do you know how to contact the care coordinator? ☐ yes ☐ no

How long does it take to have your phone calls or emails returned by the care coordinator/nurse/physician?

Has the care coordinator provided you with information on making appointments with other specialists/services?

☐ yes ☐ no

If yes, with which type of specialists?

Has the Center provided your primary care physician with a summary of your consultation?

☐ yes ☐ no ☐ I do not know

Are you promptly informed of test results? ☐ yes ☐ no

Have you been informed of what specialists and services are available to you? ☐ yes ☐ no

Have you been told that you need to see other specialists? ☐ yes ☐ no

If yes, did the care coordinator make the appointment for you? ☐ yes ☐ no

Has your psychological health been evaluated by a psychiatrist or psychologist? ☐ yes ☐ no

If you are in the process of transitioning to an adult provider, did the coordinator assist you with the transition?

yes ☐

no ☐

Please describe the process:

Advocacy

Has the Care Coordinator or other team members provided educational or emotional support such as support group referrals and access to educational resources (i.e. CARES Foundation, others affected by CAH, publications, internet resources)? ☐ yes ☐ no

Do you feel you could respond effectively -

During an emergency (adrenal crisis, dealing with ER and EMS personnel)? ☐ yes ☐ no

When interacting with other healthcare professionals ☐ yes ☐ no

Teaching and Training

Have you been provided with general information on CAH? ☐ yes ☐ no

Were you taught how to and when to administer Solu-Cortef (hydrocortisone) injection? ☐ yes ☐ no

If yes, did you have hands-on practice at teaching session? ☐ yes ☐ no

How often have you been taught how to give the injection since initial training? _____

Have you been provided resources for education and other topics (i.e. planning for school and camp, transition to adult care providers, sexuality, fertility, and other concerns)? ☐ yes ☐ no

Environment

Is the facility clean? ☐ yes ☐ no

Were you able to find the office easily? ☐ yes ☐ no

How long did you wait for the doctor? _____

How much time did the doctor spend with you? _____

Do you feel you had adequate time with the doctor? ☐ yes ☐ no

Were all your questions/concerns answered and/or addressed ☐ yes ☐ no

If no, what are they?

If you had more than one appointment or test on the same day, how well was it coordinated?

How long did you wait between appointments? _____

Did the other specialists/departments know you were coming? ☐ yes ☐ no

Were they prepared for you? ☐ yes ☐ no

After the appointment, was follow-up needed (another appointment or test results)? ☐ yes ☐ no

If yes, how long until you were contacted? _____

Speaking generally, how satisfied are you with your experience(s) at the Comprehensive Care Center? What has been going well? What would you like to see improved?

Future Needs

Will you continue to use the Center in the future?

☐ yes

☐ no

Please explain:

May CARES Foundation contact you about your responses to your experience?

☐ yes ☐ no

If yes, please provide contact information:

Name: _____

Address: _____

Email: _____

Phone number: _____

You may email your completed survey to: Dina@caresfoundation.org.

If you have not joined CARES, we would love to have you as a part of our community. You receive information on the latest in CAH research, medication recalls, conferences, support activities and more. Go to

<https://www.caresfoundation.org/join-our-community-2/>.

Thank you for completing our survey!

PLEASE FOLLOW THE INSTRUCTIONS ABOVE FOR SUBMITTING SURVEY.