The Importance of the Pediatric Patient Voice in Healthcare

Launched by Intersecting Children’s Needs and Abilities Network

Leanne West, President

iCANresearch.org
Where in the World is iCAN?

27 Chapters on 4 Continents
1 Virtual Chapter – Join Now!
Want to start a chapter?
info@iCANresearch.org
iCAN is a resource available to any organization, company, or group that seeks the input of children and families for their projects and products.
Kid Reviewed. Kid Approved.

Let everyone know that your product is iCAN approved by adding our new iCAN Seal of Approval!

After our kids review your material, and you make any recommended changes, your product can proudly display the iCAN Seal Approval.

What can be approved? Clinical trial protocols, consent, assent, educational material, medical devices, and more.
Our Kids are the Experts
“To me, iCAN has been incredibly powerful, inspiring, and humbling. It gave me the ability to speak to the smart, engaged kids who are battling various illnesses. I can think of no better way to truly be patient centric and centered.”

“Giving children and child advocacy groups a voice in drug development leads to better pediatric clinical trials, with enhanced recruitment and retention. Lessons I’ve learned and shared from iCAN have led (our company) to bring improved pediatric clinical trials to life.”

“I genuinely walked away with very concrete ways to change the way we are doing things in clinical research.”
**MDUFA IV Commitment: Patient Engagement & the Science of Patient Input**

**Patient & Caregiver Connection: Current Partners**

<table>
<thead>
<tr>
<th>iCAN</th>
<th>Global Healthy Living Foundation</th>
<th>NORD</th>
<th>NAC</th>
<th>American Sleep Apnea Association</th>
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<tbody>
<tr>
<td>TMJA</td>
<td>creakyjoints</td>
<td>COPD Foundation</td>
<td>FORCE</td>
<td>Faced Our Risk of Cancer</td>
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<td>FACES &amp; VOICES - RECOVERY</td>
<td>JDRF</td>
<td>IMPROVING LIVES: Curing Type 1 Diabetes</td>
<td>EMPowered</td>
<td>Muscular Dystrophy Association</td>
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<td>AAKP</td>
<td>North American Spinal Cord Injury Consortium</td>
<td>THE Michael J. Fox Foundation FOR Parkinson’s Research</td>
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Encourages:

- Partnership with Patients
- Fostering the Culture of Patient Engagement

icANresearch.org
Q5 As a patient or caregiver, do you currently or have you had previous experience with medical devices (been implanted with, use(d) at home, or use(d) in a clinical setting) to treat or manage the disease condition(s) listed?

Q6 Have you had any difficulties with the use or the functioning of your device(s)?

Q9 In thinking about the condition(s) you’ve referred to in this survey, what aspect(s) would be the most important to fix to improve your and your family member’s quality of life?
Hampton Woods and Jake Haygood, KIDS Georgia, age 18, talk about their medical device innovation.
Paige, age 17, Georgia

Representing iCAN

"iCAN provides a platform in which patients and caregivers can share their voice to help improve pediatric healthcare."
Advancing the Development of Pediatric Therapeutics (ADEPT 6) Workshop *Pediatric Clinical Trial Endpoints for Rare Diseases* With a Focus on Pediatric Patient Perspectives, November 12, 2019

<table>
<thead>
<tr>
<th>Name</th>
<th>State</th>
<th>Diagnosis</th>
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<tbody>
<tr>
<td>Regina, 13, TX</td>
<td>Texas</td>
<td>Spina Bifida</td>
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<tr>
<td>Ananya, 17, GA</td>
<td>Georgia</td>
<td>Salt Wasting Congenital Adrenal Hyperplasia due to 21 - Hydroxylase Deficiency</td>
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<tr>
<td>Audrey, 16, KS</td>
<td>Kansas</td>
<td>Scoliosis, Atrial Septal Defect, Craniosyntosis</td>
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<tr>
<td>Olivia, 16, MI</td>
<td>Michigan</td>
<td>Type 1 Diabetes, Hashimotos, Autoimmune Solar</td>
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<tr>
<td>Logan, 11, TX</td>
<td>Texas</td>
<td>Chronic Urticaria</td>
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<td></td>
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<td>Nephrotic Syndrome and Juvenile Psoriatic Arthritis</td>
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FDA Workshop: Evolving Role of Artificial Intelligence in Radiological Imaging, Feb 25-26, 2020

Isabella, 16 year old from KIDS Illinois

icANresearch.org
iCAN Young Professionals, age 19+

Dakota is a 24-year old patient from Texas. Dakota has lived through an incredible 15 years of medical advancements and has so many wonderful stories to share.

Dakota is an expert of all stages of pediatric life as a patient and can really express the special nuances of living with a medical condition.

Dakota currently works in public health
FDA 'Rare Disease Day' event, "Supporting the Future of Rare Disease in Product Development," April 1, 2020

Rhiannon lives with Sickle Cell Disease & Lupus
16 years old
KiDS Hope for Henry in DC
A CDRH Internal *Patient Engagement* video to help the FDA’s staff better relate to the people we serve, recorded in 2020.

“My experience at the FDA by Rhiannon for the 2020 iCAN Summit”

View Video