

Advocacy

**Epilepsy Foundation of Minnesota
Midwest Seizure Smart Conference**

October 15, 2011

**Joan Skluzacek, Founder
Dravet.org**

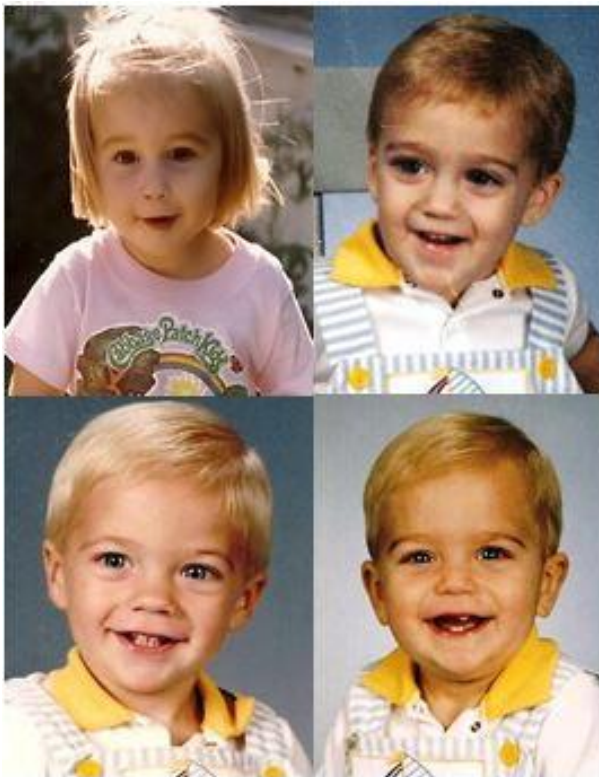
How did I become an epilepsy advocate?

- Growing up with epilepsy in my family
- Lifeguard Training
- Teaching students with epilepsy

**Suddenly, my basic understanding of epilepsy
was completely inadequate.**



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Nick's Story: What it means to have Dravet syndrome



Dravet syndrome is a spectrum within the spectrum

- **Severe, progressive epileptic encephalopathy**
- **Malignant, intractable seizures**
- **Genetic cause – SCN1A mutations**
- **Developmental and behavioral problems**
- **Many associated conditions**
- **Life-threatening**

How did I learn this?

- Information from Nick's neurologist
- Connecting with other families
- Gathering data
- Conference in Los Angeles
- Dr. Dravet's response



IDEA *League*
International Dravet Syndrome Epilepsy Action

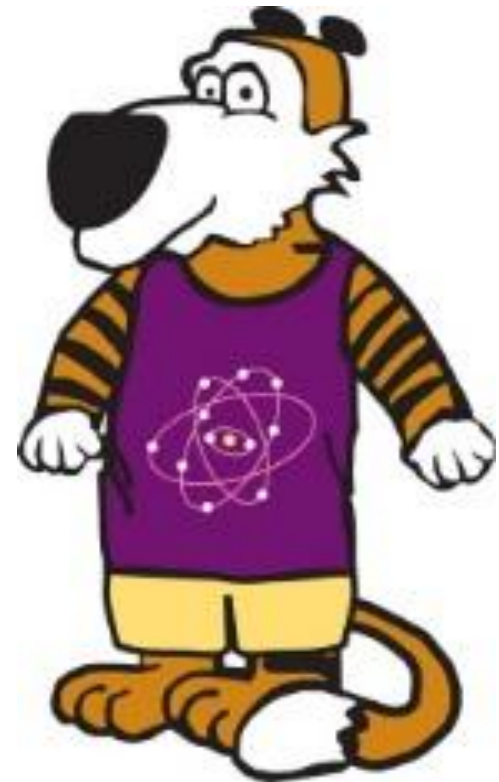
The voice for Dravet syndrome.

But... I'm such a very small animal – what can I do?



Our assets: The five “Cs”

- **Courage**
- **Caring**
- **Cause**
- **Commitment**
- **Community**



Patients are being diagnosed earlier

- **Collaborative Clinical Research & Comprehensive Care Network**
- **Sponsorship of continuing medical education for providers of medical care**
- **Co-Funded and contributed work to the publication of a supplemental issue of *Epilepsia* on Dravet syndrome**

Patients and their families now have sources of information and support to help them make important decisions and cope with Dravet syndrome

- **Comprehensive Website**
- **Printed Materials**
- **Biennial Conference**

Dravet.org is supporting promising research

- We gather and publish data from our cohort of patients and families that helps to improve patient care and to generate new hypotheses for more rigorous research
- We are partnering with researchers at NYU on a new study of SUDEP that we hope will lead to strategies for prevention
- We are funding research projects that may lead to new treatments and cures for Dravet syndrome
- We are a co-sponsor, with Vision 2020 partners, of a National Institutes of Medicine study on epilepsy. The report will be published in May 2012

Some beliefs and values that have guided my advocacy

- **Change does not happen without risk**
- **Communicate clearly – avoid ambiguous language**
- **Seek out mentorship and support - professional people who are genuinely earnest and caring can be powerful and may be great resources**

Some beliefs and values that have guided my advocacy

- Be open and form partnerships
- Bring your assets
- Advocating for my own child and family is indivisible from advocating for others

