

# The Role of the Engaging Parent/Consumers SACHDNC

# Definition of a Consumer

- One that consumes, especially one that acquires goods or services for direct use or ownership rather than for resale or use in production and manufacturing.
- One that consumes, especially one that acquires goods or services for direct use or ownership rather than for resale or use in production and manufacturing.
- **Patient** - Patient; a person who requires medical assistance.

# SACHDNG CONSUMERS

- Members of the public having special expertise about or concern with heritable disorders

# CONSUMER ADVOCATES of Newborn Screening

- Patients and families *>the experts*
- Parents of affected children with physical and neurological consequences due to lack of screening
- Parents of deceased affected children due to lack of screening
- Parents of affected children or patients detected early
- Adult patients

# Consumer Report

## 1. INAUGURAL COMMITTEE

- Majority of states-*no expanded NBS*
- Supplemental screening information not provided to families
- High number of diagnosed disorders in ERs and ICUs with child in crisis
- Consumer member on committee
- Public Comment-*only opportunity for other input*

# Consumer Report Continued

## 2. **TWENTY FIFTH COMMITTEE MEETING**

- ACMG recommendation to states to inform of supplemental screening-*after 1 meeting!*
- All states have expanded NBS
- Babies are diagnosed with NBS
- Newborn Screening Saves Lives Act
- Consumer member on committee
- Consumers integrated in all three subcommittees of the advisory committee
- Consumer voice included in regional collaboratives; committee initiatives like the “*Clearing House*”
- The medical profession and the public are more educated on NBS and heritable disorders than ever before.

# Quote from an Adult Consumer

- **If you are an adult with an OA it is just about impossible to convey an urgency to the medical profession. The local resource would like to see me in 7 months for example. It is cruel. In most cases but not all, as your family members with an OA become adults, the main protection they have, you, will no longer be in the same house. The voice of you as a patient will never be as demanding as a parent for a child. The interest in a patient must not just be when they are on a gurney in the ER! You do not have time to educate the ER staff**

# ADVOCACY GROUPS

- Representation of the diversity of consumers, *both pediatric and adult*
- Disease specific
- Distinct needs and concerns related to newborn screening
- Critical entity of committee discussions
- Come with first hand experience and expertise

# Increasing Consumer Involvement

- Increase consumer representation on the committee,
- Public comment is good but “Time for dialogue” is needed
- Collaborate with groups for information and data collecting
- Possible scholarship funding for consumers attendance at meetings
- Partner with consumers and advocacy groups with committee initiatives, ie “Clearing House”; representation with Regional Collaboratives;
- Encourage providers to link newly diagnosed patients and families to advocacy groups to begin overall collaboration and information sharing
- (parents of older kids are just now linking to organizations due to lack of awareness-*isolation*)

# Advocacy Groups and the Nomination Process

- Submit nominations for disorders to consider
- Provide disorder specific information
- Participate in evidence review workgroup discussions
- Consumers of disorders yet to be included on the recommended panel are critical stakeholders

# Consumer Viewpoint

- The adoption and success of NBS and related issues, will depend on whether the needs and concerns of consumers and advocacy groups are addressed and harnessed as a driver in the medical profession and public, or whether they will lead to apprehension and distrust from the public stake holders.

# SACHDNC SUCCESS

## A Child's Future

