



## Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST) Navigating the School System

### What to do before your child enters school...

- Educate your child about their skin condition
- Contact your child's school the year before they enter so they can be prepared to handle your child (educate staff, medical plan, AC in classrooms, etc.)
- Early Intervention services will assist with any developmental delays present

### Daycare/Nursery/Preschool

- Send home notes to other parents in class/school to educate them about ichthyosis
- Ask to speak to parents at Back-to-School Night or orientation about ichthyosis; this will alleviate any questions/concerns they may have (Is it contagious? Were they in a fire?) etc.
- If child is old enough, allow them to talk to classmates about ichthyosis. Children will wonder why child has lotion on each day. Simple answers will satisfy young ones
- Ask about outdoor playtime-is there a shaded area? If too hot, where will your child go? Are all classrooms air conditioned?

### Elementary School

- Bring your child to visit new school and staff before the year starts
- Discuss child's special needs with principal, nurse, teacher and psychologist
- Educate your child's class about ichthyosis-who will do this? Parent, teacher, child, psychologist?
- Provide school with copy of FIRST's publication *Ichthyosis: A Guide for Teachers*
- 504 Plan is a good idea
  - Lists specifics about your child's medical needs
  - What is done when child gets too hot for gym? (frequent breaks, sunglasses, hats, cooling vest, etc.)
  - He/she may bring a water bottle to all classes
  - Hat allowed in school due to loss of hair
  - Recess?
  - Child must report to nurse to apply creams/lotions whenever necessary (who will apply them-child or nurse?)
  - Air conditioners/fans must be in classrooms
  - Special transportation if necessary

- IEP
  - Necessary if your child requires special accommodations for educational reasons
  - OT/PT/Speech
- School trips/Activities
  - Distance of trip? Bus too hot? Lotions on trip? Chaperoned by??
  - Field Day-how can my child participate without overheating?
  - Graduation/Moving-up ceremonies-location? AC?

### **Middle School**

- Transitioning to new school
- Meet with new principal and nurse to discuss and educate
- Meet/email teachers; communication is key
- New children may enter from other schools-don't know about ichthyosis
- Children change classes- will all rooms have AC?
- Self-esteem issues arise due to peer pressure
- 504 Plan/IEP continue-might have to add to plan
- Seek professional help for your child if needed
- Middle School is tough for everyone, but ichthyosis adds to it
- Trips/Activities
- Encourage child to join clubs; get involved
- Rough years

### **High School**

- Transitioning to new school
- Meet with new principal and nurse to discuss and educate
- Meet/E-mail teachers; communication is key
- Encourage child to join clubs; get involved
- By now, most children are sure of who they are and it is easier to be "one of the group"
- 504 Plan/IEP continue-might have to add to plan
- Trips/Activities

### **Other**

- Stay involved (volunteer, class parent, etc.)
- Talk to your child, discuss their day, ask how others react to them
- Point out your child's strengths
- Be prepared for rough days! You will hear: *I hate my skin! This is YOUR fault! I don't like what I look like! I want normal skin! etc.*
- Talk to others who have already walked in your shoes
- Contact FIRST for resources to help (DVDs, publications)