



International Association of
Hidradenitis Suppurativa Network, Inc.

Supporting Your Child with HS

A PARENT'S GUIDE

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www.iahsn.org

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Introduction

Supporting a child with Hidradenitis Suppurativa (HS) involves unique challenges that affect their physical, emotional, and social well-being. This guide provides practical tips for communicating with school staff, explaining HS to your child in an age-appropriate way, and fostering resilience at home. Together, these steps can help create a supportive environment where your child feels understood, empowered, and confident in managing HS.



Welcome

Welcome to your guide for supporting children with Hidradenitis Suppurativa (HS). Whether you're navigating school accommodations, helping your child understand their condition, or building resilience together at home, this guide is here to provide you with practical tools, compassionate advice, and encouragement. Our goal is to empower you and your child with the resources needed to face HS confidently and foster a nurturing environment where they feel supported every step of the way. Let's embark on this journey together, creating a foundation of understanding, strength, and hope.



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Module 1

COMMUNICATING WITH YOUR CHILD'S SCHOOL

1. Schedule an Initial Meeting

- **Meet Key Staff:** Arrange a meeting with your child's teacher, counselor, school nurse, and, if possible, any additional staff who interact with your child regularly.
- **Explain HS:** Provide a simple, clear explanation of HS and how it affects your child. This might include discussing symptoms, potential pain or discomfort, and how it can impact their school day.
- **Use Resources:** Bring along brochures or information sheets to help school staff better understand HS and its impact.

2. Outline Necessary Accommodations

- **Flexible Arrangements:** Discuss any accommodations that might help your child, such as:
 - Adjusted seating for comfort
 - Extra time to transition between classes
 - Access to a private area in the nurse's office if symptoms flare up
- **PE Modifications:** If physical activity aggravates symptoms, ask for alternatives to standard physical education activities that suit your child's needs.

3. Develop an Individualized Health Plan

- **Create a Health Plan:** Work with the school nurse and counselor to create a health plan specific to your child's needs. Include details on how to handle flare-ups, the necessity of restroom breaks, and any emergency care if required.
- **Outline Emergency Protocols:** Make sure staff knows how to respond to symptoms during the school day and when to contact you if needed.

4. Emphasize Privacy and Sensitivity

- **Request Privacy:** Ask staff to respect your child's privacy regarding HS and to approach the topic with sensitivity. This includes ensuring other students aren't made aware of your child's condition without consent.
- **Encourage Empathy:** Gently remind staff of the importance of empathy, as children with HS can feel self-conscious about their condition.

5. Schedule Regular Check-Ins

- **Stay in Touch:** Set up regular check-ins with teachers or counselors to stay informed about how your child is doing and any new challenges that may arise.
- **Encourage Feedback:** Let your child know they can come to you with any concerns or issues they experience at school related to HS.

Roadmap to Communicate

1: SCHEDULE AN INITIAL MEETING

2: EXPLAIN YOUR CHILD'S NEEDS AND DISCUSS ACCOMMODATIONS

3: EXPLAIN YOUR CHILD'S NEEDS AND DISCUSS ACCOMMODATIONS

4: MAINTAIN REGULAR CHECK-INS WITH SCHOOL STAFF

5: EMPOWER YOUR CHILD TO SELF-ADVOCATE

EMPOWER YOUR CHILD TO SELF-ADVOCATE

Self-Advocate

- **Teach Simple Communication Skills:** Help your child practice simple phrases to request support, such as asking for a break, accessing the nurse, or explaining discomfort to a teacher.
- **Build Confidence:** Encourage your child to communicate their needs without fear or embarrassment, fostering a sense of independence and self-advocacy.
- **Support Social Connections:** Work with school staff to ensure your child has opportunities for social inclusion, such as group activities or buddy systems.

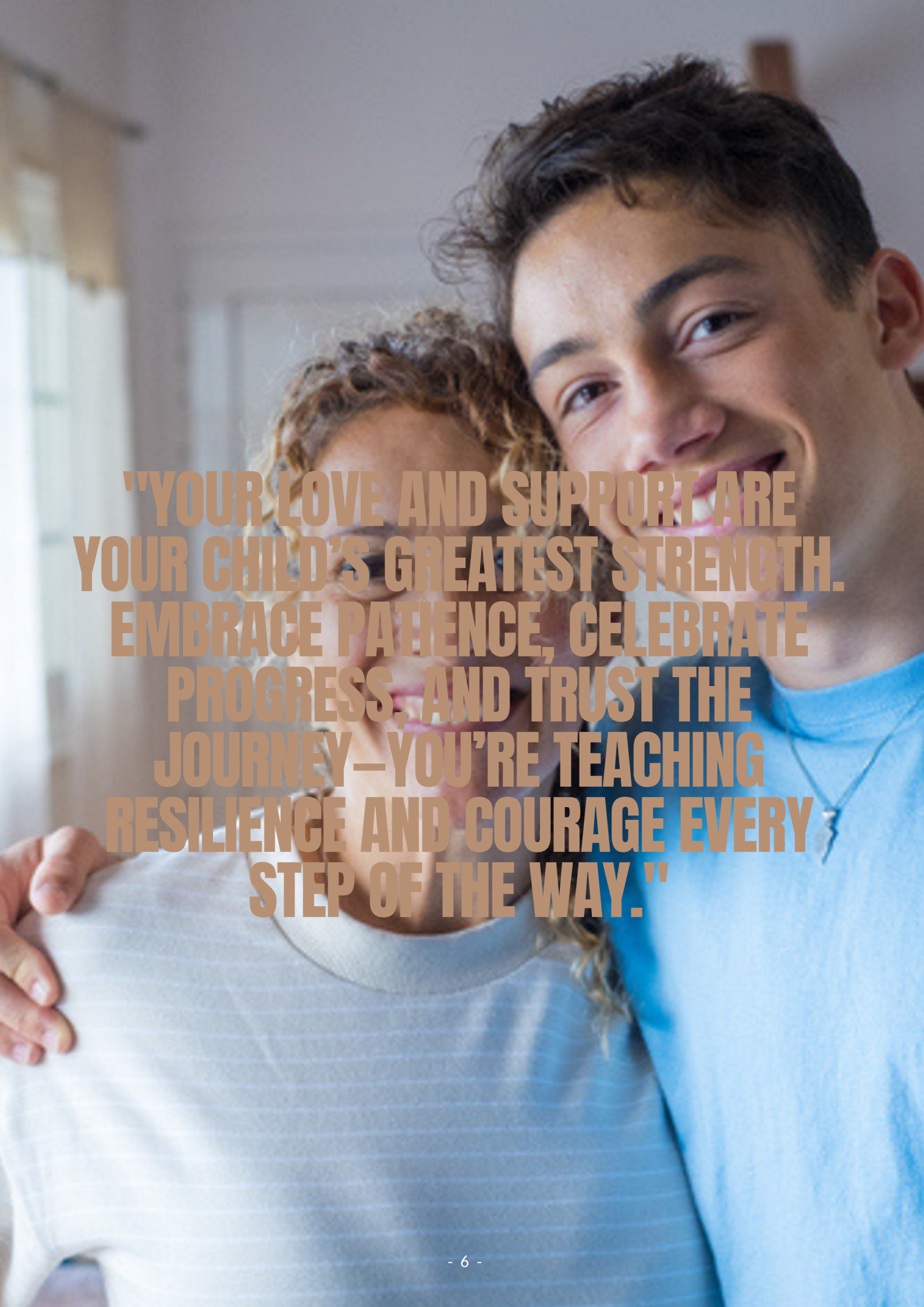
Address Any Issues Promptly

- **Monitor for Bullying or Exclusion:** Ask the school to be vigilant about any signs of bullying or exclusion related to your child's condition.
- **Encourage Empathy Activities:** Suggest empathy and inclusion activities that help classmates understand chronic conditions, promoting kindness and respect in the classroom.
- **Speak Up When Needed:** If issues arise, communicate directly with the school to resolve them quickly and maintain a positive environment for your child.

"Supporting my child's well-being is our shared goal. Open communication and understanding can make a meaningful difference, allowing them to thrive both academically and emotionally. Together, we can create a compassionate environment where they feel safe, valued, and empowered."

Celebrate Progress and Stay Flexible

- **Acknowledge Successes:** Celebrate any positive changes, such as your child's ability to self-advocate or increased comfort in the school setting.
- **Adjust as Needed:** As your child grows and their needs evolve, revisit the health plan and adjust accommodations to ensure continued support.

A young man and woman are smiling together. The man is on the right, wearing a blue t-shirt, with his hand on the woman's shoulder. The woman is on the left, wearing a white t-shirt with thin blue horizontal stripes. They are both looking towards the camera. The background is a bright, slightly out-of-focus indoor setting.

"YOUR LOVE AND SUPPORT ARE YOUR CHILD'S GREATEST STRENGTH. EMBRACE PATIENCE, CELEBRATE PROGRESS, AND TRUST THE JOURNEY—YOU'RE TEACHING RESILIENCE AND COURAGE EVERY STEP OF THE WAY."

Identifying Your Child's or Teen's Needs

Supporting a child with Hidradenitis Suppurativa (HS) in the school environment requires understanding the specific ways this condition impacts their daily experience. By identifying their unique needs and collaborating with school staff, you can help create a safe, inclusive, and supportive environment that promotes both learning and well-being.

MIND MAP

**OBSERVE
BEHAVIORAL AND
SOCIAL CUES**

**ASSESS PHYSICAL
NEEDS IN THE
CLASSROOM**

CHILD | TEEN

**COLLABORATE ON
ACADEMIC
ACCOMMODATIONS**

**IDENTIFY
EMOTIONAL AND
SOCIAL NEEDS**



Module 2

**EXPLAINING HS TO YOUR CHILD IN A
POSITIVE WAY**

02

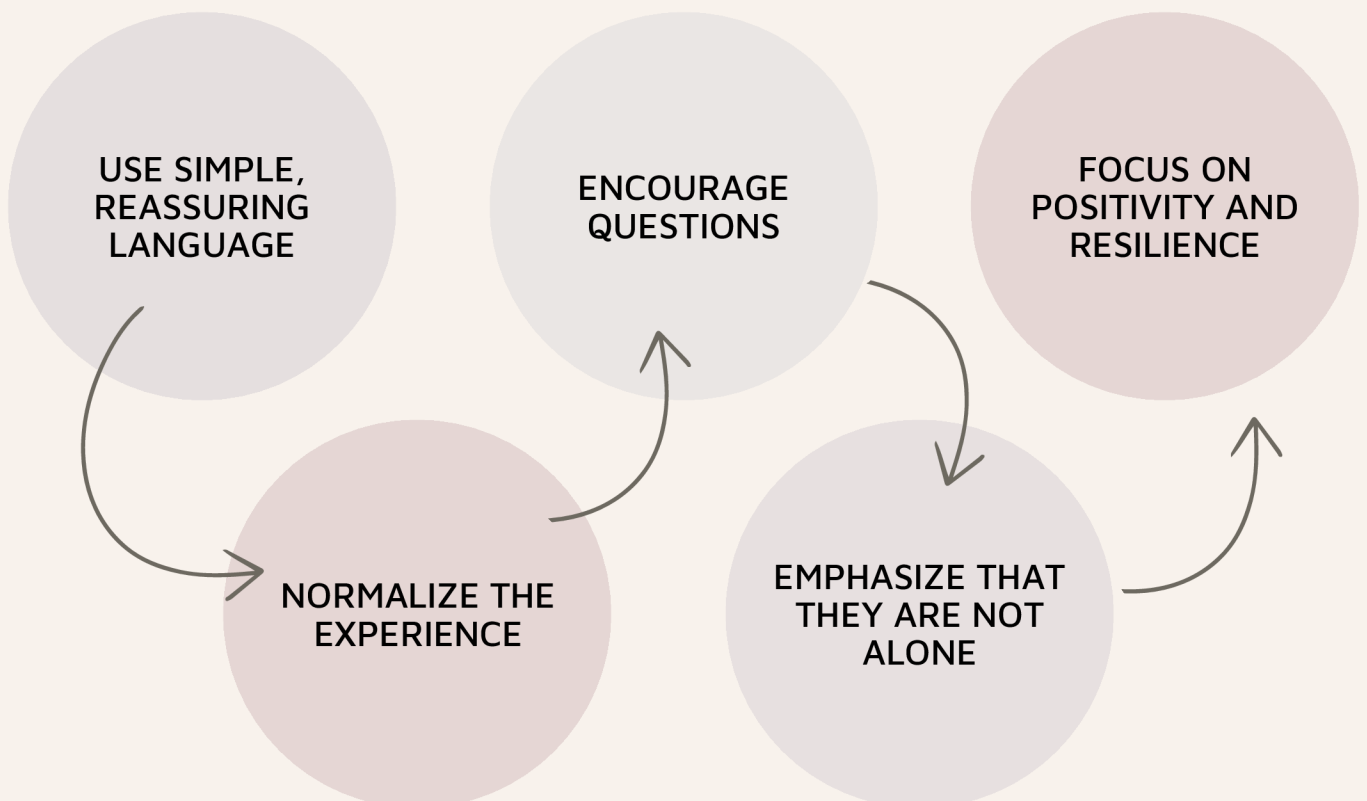
Module 2

EXPLAINING HS TO YOUR CHILD IN A POSITIVE WAY

Reframing HS

Talking to your child about Hidradenitis Suppurativa (HS) can be challenging, but framing it in a positive, empowering way can help them understand their condition without fear or embarrassment. Here are some tips for creating an open and supportive conversation:

Reframing HS Diagram





Module 2

REFRAMING HS

Reframing

Talking to your child about Hidradenitis Suppurativa (HS) can be challenging, but framing it in a positive, empowering way can help them understand their condition without fear or embarrassment. Here are some tips for creating an open and supportive conversation:

Use Simple, Reassuring Language

- **Describe HS Simply:** Explain HS in terms they can understand, such as, “HS is a condition that causes bumps or sores on your skin. It doesn’t happen because of anything you did, and it’s not something others can catch from you.”
- **Emphasize What’s Manageable:** Reassure them that while HS can be uncomfortable, there are ways to manage it. Share how self-care and support from loved ones help make things better.

2. Normalize the Experience

- **Compare to Other Conditions:** You might say, “Just like some kids have allergies or asthma, you have HS. It’s just one way bodies can be different.”
- **Highlight Their Strengths:** Focus on what makes them unique outside of HS, emphasizing skills, interests, and qualities they have that aren’t defined by their condition.

3. Encourage Questions

- **Invite Curiosity:** Let them know it’s okay to ask questions and express their feelings about HS. For example, “If you’re ever wondering why something is happening or feel confused, you can always talk to me.”
- **Answer Openly:** Respond to their questions with honesty, but keep it simple and reassuring. It’s okay to admit if you don’t have all the answers and offer to learn together.

4. Emphasize That They Are Not Alone

- **Share Stories of Others:** Mention that many people live with HS and manage it successfully. Knowing they aren’t alone can help them feel supported and reduce any sense of isolation.
- **Talk About Their Support Team:** Remind them that they have family, friends, and doctors who are there to help, and together, you’re all working to keep them feeling their best.

5. Focus on Positivity and Resilience

- **Highlight Resilience:** Talk about how living with HS helps them grow stronger and more resilient. For example, “You’re learning how to take care of yourself and handle challenges, which makes you really strong and brave.”
- **Empower Self-Care:** Frame self-care as a positive choice that helps them feel their best, rather than as a burden.



Module 3

FOSTERING RESILIENCE AND SELF-ESTEEM AT HOME

Resilience and Self-Esteem

Building resilience and self-esteem in your child provides them with lifelong tools to face challenges confidently. Here are key ways to nurture these strengths at home:

1. Encourage Open Communication

- **Create a Safe Space:** Let your child know it's okay to express feelings of frustration, sadness, or worry. Listening without judgment reinforces their sense of being valued and understood.
- **Name Emotions:** Help your child identify and name their emotions. This builds emotional awareness and helps them process feelings constructively.

2. Celebrate Strengths and Small Wins

- **Acknowledge Efforts:** Recognize both big and small achievements, from finishing a project to managing a tough day. Positive reinforcement boosts their confidence and reinforces their ability to handle challenges.
- **Highlight Unique Strengths:** Remind your child of their individual strengths and abilities outside of their condition, helping them see themselves in a positive light.

3. Teach Problem-Solving Skills

- **Practice Solutions Together:** Encourage your child to think through problems and brainstorm solutions, fostering independence and confidence in their own decision-making.
- **Model Resilience:** Demonstrate resilience in your own actions by sharing examples of how you handle obstacles with a positive mindset.

4. Encourage Self-Care and Healthy Habits

- **Routine Self-Care:** Teach your child the importance of self-care, from taking care of their skin to practicing relaxation techniques like deep breathing or mindfulness.
- **Set Goals:** Help them set small, achievable goals that give them a sense of accomplishment and motivate them to keep moving forward.

5. Foster Positive Social Connections

- **Encourage Friendships:** Support relationships with peers who are understanding and inclusive. Feeling connected and supported by friends can greatly boost your child's self-esteem.
- **Build a Support Network:** Consider finding support groups or communities where your child can connect with others who understand their experiences.

A photograph of a diverse family of four—two adults and two children—smiling and embracing each other outdoors. The background is a soft-focus green, suggesting a park or garden setting. The family members are dressed in casual, bright clothing.

CONCLUSION

Supporting your child with Hidradenitis Suppurativa (HS) is a journey that requires patience, understanding, and resilience. By advocating for their needs, fostering open communication, and building a strong foundation of support at home and at school, you empower your child to navigate their condition with confidence and strength. Every step you take to ensure they feel understood, valued, and cared for makes a lasting impact on their well-being and self-esteem.

Remember, you're not alone in this journey. Lean on resources, stay connected with school and healthcare professionals, and encourage your child to express their needs openly. Together, you can help them embrace their strengths, build resilience, and create a positive future. Thank you for your dedication and support—your efforts make all the difference in helping your child thrive.

**"YOUR STRENGTH AND LOVE
GUIDE YOUR CHILD'S
RESILIENCE. YOU'RE MAKING A
DIFFERENCE EVERY SINGLE
DAY."**



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