FIRST Launches Groundbreaking Patient Survey to Elevate the Voice of the Ichthyosis Community

The Foundation for Ichthyosis & Related Skin Types, Inc., or FIRST, is a dedicated CSD patient group member working to elevate the real-world experiences of people living with ichthyosis, a group of genetic skin disorders characterized by dry, thickened and scaly skin. As part of that commitment, FIRST recently launched the Patient Voice Survey, the first comprehensive survey designed to capture the real-world experiences and unmet needs of people living with ichthyosis.

While the physical symptoms of ichthyosis are well documented, far less has been captured about the day-to-day challenges patients face. Through the Patient Voice Survey, FIRST sought to understand the emotional, social, financial and healthcare challenges faced by patients. The findings can help improve future research and clinical care, as well as strengthen advocacy efforts and guide the development of patient-centered treatments.

Key survey findings include:

- 9 in 10 patients reported that ichthyosis has emotional impacts, while 8 in 10 reported impacts to their social life.
- 7 in 10 patients said their treatment regimen is difficult to follow, with 1 in 5 spending $200 or more per month on supplies.
- More than half of patients experienced delays in receiving a correct diagnosis, with two-thirds of respondents reporting it was difficult to find a provider who understands ichthyosis or is willing to learn about it.
- Respondents also identified that patients and families need more support. This includes access to specialists, educational materials, peer support, mental health resources, financial assistance and clearer treatment information.
- 85 percent of patients identified new treatments as key research priority.

FIRST's Patient Voice Survey reflects the vital role CSD member organizations play in advancing patient-centered research, education and advocacy across the skin disease community. By capturing and elevating the lived experiences of people living with ichthyosis, FIRST is helping build the evidence needed to improve care, inform policy and drive innovation. These efforts align CSD's broader mission to amplify the voices of patients and families, foster collaboration among member organizations and advance initiatives that address the shared challenges faced by individuals living with skin diseases. Through the collective work of organizations like FIRST, CSD continues to strengthen its impact and ensure that patient perspectives remain at the center of research, treatment and advocacy efforts.

By documenting these experiences, FIRST is helping ensure the voices of patients and families are reflected in research, healthcare decision-making and policy discussions. The survey findings underscore the need for continued investment in education, support and innovation to improve outcomes for the ichthyosis community.