QUALITY IMPROVEMENT

Enhancing Immune Thrombocytopenia Education and Support: Insights From a Learning Exchange Program

MICHAEL TARANTINO,[1] MD, DAVID DUBINSKI,[2] MBA, COREY FALCON,[3] MD, LESLIE FERBER,[2] MPH, PATRICK FOY,[4] MD, STEPHANIE JOHNSTON,[5] MSN, APRN, FNP-C, AOCNP, SUSAN KIRK,[6] PA-C, MICHELE P. LAMBERT,[7] MD, MSTR, FARISHTA MANZOOR,[8] PharmD, VLAD RADULESCU,[9] MD, IBERIA ROMINA SOSA,[10] MD, PhD, and PORCHER SCOTT[11]

From [1]University of Illinois Chicago College of Medicine at Peoria, Peoria, Illinois; [2]Sobi Inc., Waltham, Massachusetts; [3]Ochsner Children's Hospital, New Orleans, Louisiana; [4]Medical College of Wisconsin, Milwaukee, Wisconsin; [5]Barrow Neurological Institute, Phoenix, Arizona; [6]Baylor College of Medicine, Houston, Texas; [7]The Children's Hospital of Philadelphia, Philadelphia, Pennsylvania; [8]Dana-Farber Cancer Institute, Boston, Massachusetts; [9]University of Kentucky, Lexington, Kentucky; [10]Fox Chase Cancer Center, Philadelphia, Pennsylvania; [11]ITP-In Pregnancy, Georgetown, South Carolina

Authors' disclosures of conflicts of interest are found at the end of this article.

Correspondence to: Michael Tarantino, University of Illinois Chicago College of Medicine at Peoria, 1 Illini Dr., Peoria, IL 61605

E-mail: mtarantino@ilbcdi.org

https://doi.org/10.6004/jadpro.2026.17.7.7

J Adv Pract Oncol 2026

Abstract

Background: Immune thrombocytopenia (ITP) is a rare autoimmune disorder resulting in reduced platelet count. The annual incidence is 3.3 per 100,000 adults and 8.8 per 100,000 person-years in children. Immune thrombocytopenia impacts the quality of life, productivity, and psychosocial well-being of patients and caregivers. This quality improvement study aims to characterize needs of patients, caregivers, and health-care providers (HCPs) managing chronic ITP to improve management in the future. **Methods:** We conducted a two-session Learning Exchange program: one with HCPs and adult patients, and one with HCPs and caregivers of pediatric patients. Discussions encompassed clinical and personal experiences with chronic ITP, the health-care system, and support resources. Session transcripts identified key themes, which participants subsequently prioritized in a post-meeting survey. **Results:** A total of 7 patients, 6 caregivers, and 14 HCPs participated in the Learning Exchange sessions, discussing challenges in chronic ITP management and areas for improvement. Post-meeting surveys identified shared priorities, ranked as follows: (1) empowering patients to self-advocate; (2) strengthening shared decision-making; (3) improving resources and support; (4) following the evolving treatment landscape; and (5) mental health support. **Conclusions:** The sessions identified key needs involving improved education for patients, caregivers, and HCPs; improved communication between patients, caregivers, and HCPs; the greater need for self-advocacy and shared decision-making; and the desire for better support resources and networks. This knowledge will enable the development of improved educational resources, support programs, and future research to benefit the chronic ITP community and improve the quality of management of chronic ITP for patients, caregivers, and HCPs.

Immune thrombocytopenia (ITP) is an autoimmune disorder characterized by megakaryocyte destruction in the bone marrow and/or antibody-mediated platelet destruction in the blood, leading to a decreased platelet count (Petito & Gresele, 2024). Patients often present with bleeding symptoms, including petechiae, purpura, epistaxis, gingival bleeding, hematomas, hematuria, heavy menstruation, or fatigue (U.S. Department of Health and Human Services, 2022). Severe cases can cause life-threatening intracranial hemorrhage or massive internal bleeding (Kohli & Chaturvedi, 2019). The incidence of ITP is estimated at 8.8 cases per 100,000 person-years for children and 3.3 cases per 100,000 person-years for adults (Kühne et al., 2011; Shaw et al., 2020). Data from one state suggest an age-adjusted prevalence of 9.5 per 100,000 people (Segal & Powe, 2006).

Immune thrombocytopenia is categorized by duration as acute (< 3 months), persistent (3–12 months), or chronic (> 12 months). It may be idiopathic or triggered by bacterial or viral infection, vaccination, certain medications, or other immune stressors. Spontaneous resolution is more common in children than in adults, and approximately 70% of pediatric cases are managed only by monitoring platelet count or close observation for bleeding (Harris et al., 2023; Schultz et al., 2014).

Treatment recommendations depend on platelet count, bleeding history, disease stage, severity, comorbidities, and quality-of-life goals. Acute ITP management aims to increase platelet count to a threshold that prevents or treats bleeding. For adult patients with platelet counts $< 30{,}000/\text{mm}^3$ or with active bleeding, corticosteroids with or without intravenous immunoglobulin (IVIG) are commonly recommended, while hospitalization may be advised for those with counts $< 20{,}000/\text{mm}^3$. Management ultimately depends on individual patient attributes and health-care provider (HCP) experience. First-line therapies include corticosteroids (prednisone, methylprednisolone, or dexamethasone), immunoglobulin (anti-D), or immunoglobulin (IVIG). Second-line options include thrombopoietin receptor agonists (TPO-RAs [avatrombopag, eltrombopag], rituximab, fostamatinib, and romiplostim). Splenectomy can be considered in some individuals. Additional agents like azathioprine offer options for refractory cases, while platelet transfusions are limited to life-threatening bleeding (Neunert et al., 2019). About 70% of children and 56% of adults achieve remission within 2 years (Schifferli et al., 2018). The significant percentage of patients with chronic ITP suggests gaps in the medical armamentarium and opportunities for emerging therapeutics, as well as for advocacy group support as patients strive to cope and achieve resolution.

Persistent and chronic ITP diagnoses significantly affect health-related quality of life (HRQoL) for both patients and caregivers. Effective treatment may help, but many still report ongoing fear, depression, anxiety, and disruption in work, school, and social life (Cooper et al., 2021; Trotter & Hill, 2018). An international patient experience survey described fatigue, reduced energy, worry about disease progression, and limitations in social and work participation as among the most common and debilitating challenges in ITP. More than half of patients report needing support with daily activities, and more than one third experience major limitations in productivity or emotional well-being (Cooper et al., 2021). Recent large-scale surveys, such as the I–WISh study, confirm that fatigue, limited energy, worry about disease progression, and reduced social and work participation are among the most prevalent and debilitating aspects of ITP for both patients and caregivers. More than half of patients report needing assistance with daily activities, and more than one third experience substantial limitations in work productivity or emotional well-being due to their disease. It is expected that aligned understanding between patients and clinicians on the emotional and physical symptom burden of ITP may facilitate shared decision-making, improve HRQoL, enable appropriate treatment selection, and accelerate achievement of treatment goals ultimately to improve future quality of care for people with chronic ITP.

Despite growing recognition of ITP's impact on HRQoL, the personal experiences and perspectives of patients and family members throughout the diagnostic journey and treatment process are lacking. We used learning exchanges to address these gaps and to identify opportunities to optimize ITP care.

METHODS

Sobi (Swedish Orphan Biovitrum AB), a rare disease pharmaceutical company developing novel therapeutics for ITP, sought to better understand the challenges and perceptions of ITP diagnosis and chronic ITP management for patients/caregivers and HCPs to facilitate advocacy efforts and ensure that novel therapeutics and disease education efforts address unmet needs. Sobi worked alongside the Platelet Disorder Support Association (PDSA) and the Foundation for Women & Girls with Blood Disorders (FWGBD) on this effort and engaged Sensified, a health-care communications agency, to organize two Learning Exchange sessions to discuss chronic ITP with patients, caregivers, and HCPs.

The Learning Exchange platform provided a structured, collaborative, and respectful forum for patients, caregivers, and HCPs to engage in meaningful dialogue. This approach—consistent with participatory and qualitative methods from health-care quality improvement, stakeholder engagement, and market research—promoted balanced conversation and reduced power imbalances. During each session, participants alternated between patient/caregiver-only discussion, provider-only discussion, and a joint session fostering open, two-way communication. One session included parents and caregivers of pediatric patients with chronic ITP, as well as an adult patient diagnosed in childhood; the other comprised adult patients and clinicians treating adult ITP. This approach has demonstrated acceptability, feasibility, and utility for exchange in health-care improvement and other community settings (McLinden et al., 2019; Mier-Alpaño et al., 2022). Participants were recruited through the PDSA, which informed patients, caregivers, and HCPs that if they were interested in participating, they would need to share their story with PDSA's industry partner, be on-camera, and agree to filming and the use of their story and image. This language was used as the basis for participant consent. Participants were compensated for their time. Institutional review board review was not sought because this was a quality improvement study that did not include research of human subjects and included only interactions involving interview procedures. However, the concept of this forum, as well as discussion points and slides, were reviewed by PDSA and Sobi legal and compliance review committees prior to the meeting.

Members of Sensified and Sobi's advocacy team jointly facilitated the Learning Exchange sessions with the meeting chair (author MT). Moderators for each session provided a list of discussion questions as general prompts (e.g., "How long did it take you [your child] to get an ITP diagnosis, and what has the treatment journey looked like since?" for patient/parent/caregiver discussion and "How do you and/or your office typically approach the treatment discussion for patients and families?" for HCPs). However, participants were free to discuss whatever they felt was important. The sessions were held virtually and lasted about 2 hours each: 10 minutes for introductory comments, 30 minutes for patient/caregiver-only discussion, 30 minutes for HCP-only discussion, 45 minutes for group discussion, and 5 minutes for closing remarks. Participants also answered a digital follow-up survey to gather feedback on the event and the session's key themes. Transcripts from the Learning Exchange sessions and comments from post-session surveys were analyzed in a qualitative, iterative review process by Sensified to identify key topics and themes; findings were summarized and organized into overarching domains.

RESULTS

Each session was conducted as scheduled in August 2024 with all consented participants in attendance. Table 1 describes basic characteristics of patient, caregiver, and HCP attendees. Duration of diagnosis ranged from 5 years to more than 40 years in adult participants who reported duration ($n = 4$); the range was approximately 12 months to 18 years in the pediatric group.

Findings from both sessions were categorized into domains that cover topics across the diagnostic and treatment journey for chronic ITP, in both pediatric and adult patients, and appear in Table 2 (patients/caregivers), Table 3 (HCPs), and Table 4 (group). Eighteen Learning Exchange participants replied to the post-session survey: 4 patients living with ITP, 3 caregivers, 2 community HCPs, and 9 HCPs from academic centers. Participants were asked to rank the importance of five key takeaway themes from the

Table 1. Participant Summary

	Patients or caregivers	Health-care providers
Session 1: Pediatric Chronic ITP, *N*	7 (6 caregivers, 1 adult patient diagnosed as a child)	6 (3 MDs, 1 NP, 2 PA-Cs)
Male, *n*	1	2
Female, *n*	6	4
Session 2: Adult Chronic ITP, *N*	6 (5 adult patients diagnosed as adults, 1 adult diagnosed as a teen)	8 (3 MDs, 2 DOs, 1 PharmD, 1 NP, 1 RN)
Male, *n*	1	3
Female, *n*	5	5
Total, *N*	13	14

Note. DO = doctor of osteopathy; ITP = immune thrombocytopenia; MD = medical doctor; NP = nurse practitioner; PA-C = physician assistant, certified; PharmD = doctor of pharmacy; RN = registered nurse.

meeting. Results of their ranked scores for perceived importance can be found in Table 5.

In the post-session surveys, patients/caregivers and HCPs agreed on what they felt were the key themes and takeaways from their Learning Exchange sessions, ranking "empowering patients to self-advocate" and "strengthening shared decision-making" as the most important takeaways, followed by the need to "improve resources and support." For both patients/caregivers and HCPs, "following the evolving treatment landscape" and "mental health support" were considered less salient summaries of the Learning Exchange's key themes.

Post-session survey respondents were also invited to submit free-text comments about their experience with the Learning Exchange sessions. Comments were positive overall and described how attendees learned from the experience.

Sample comments from patients/caregivers include: "While my experience has been like a rollercoaster ride, and I went through many different treatment options before TPO-RA was approved, I never had any 'freak out' moments that I hear others speak of. Hearing them makes me thankful that I've never been through anything I didn't feel I could manage," and "I thoroughly enjoyed the open, honest communication that doctors and patients shared with one another. I think we should have more of those."

Sample comments from HCPs include: "I gained significant insights into addressing patient needs and the importance of being an advocate for them," "I was enlightened from the information, particularly from the parents of children with ITP. It was really helpful to hear their experiences and what went well and didn't go well," "I learned about patient perspectives, mainly about how they interpret the doctor's attitudes, demeanors, and recommendations," and "I enjoyed the interaction of multiple different professionals (RN, PharmD, NP, MD) and then engaging with patients and hearing their stories. Very unique forum."

CONCLUSIONS

Common topics across both Learning Exchange sessions revolved around the emotional experiences and perceptions of patients/caregivers, the need for improved communication, the gap in education for patients and HCPs, and the need for more ITP-specific resources and support.

At diagnosis and beyond, patients and caregivers highlighted a significant unmet need in terms of education, resources, and support. As they were coping with a rare, new diagnosis and struggling to understand treatment options, many felt anxious, isolated, confused, or frustrated. They felt they lacked the desired level of support or information to help them adjust to life with the condition. Some felt this was exacerbated by lack of HCP expertise, the uncertainty of whether the condition would resolve spontaneously, and anxiety about whether the selected treatment—particularly for patients receiving monitoring only—was the optimal approach. Health-care providers should be aware of the psychosocial toll of chronic ITP, in particular the anxiety of awaiting results from bloodwork,

Table 2. Theme-Based Insights From Learning Exchange Sessions: Patient and Caregiver Insights, With Selected Supportive Quotes

Theme	Insights
Diagnosis	*Adult session* • **Diagnosis Timeline:** The time from first symptoms to diagnosis varies widely, from immediate to delays of up to 13 years • **Initial Isolation:** After diagnosis, patients often felt isolated and lacked resources and support » "Even a few years after diagnosis, I thought I was the only person in the world diagnosed with it. I didn't have any resources, any education, or anyone to talk to." • **Genetics:** While ITP typically does not run in families, some participants reported having family members with chronic ITP
	Pediatric caregiver session • **Faster Diagnosis for Children:** Children with ITP are often diagnosed more quickly than adults, possibly due to parents being more observant and proactive • **Parent Anxiety:** Initial diagnosis often brings significant anxiety and uncertainty for parents, though confirmation of ITP can alleviate fears of potentially more serious conditions like leukemia or lymphoma. More comprehensive information and support are needed at the time of diagnosis to help parents stay calm and advocate effectively » "We had no idea what ITP was so we were really relying on our pediatrician and our hematologist to understand. As a parent of a small child who they're saying can't hit her head or get a cut – that's scary…In the beginning we needed more explanation from our healthcare team. We had to ask so many questions to get what we needed." • **Initial Treatment Experience:** Treatments commonly start with steroids or a "watch and wait" approach, with parents relying heavily on HCPs due to limited initial knowledge. Some parents struggle with the uncertainty of waiting for treatment outcomes and feeling inadequate in their ability to influence the situation » "The hardest part was waiting to see what to do. We went and got a second opinion because I wanted to do something for her."
Resources and support	*Adult session* • **Self-Advocacy:** Patients see themselves as experts on their own bodies and feel a constant need to advocate for themselves • **Desire for Peer Connection:** There is a demand for focused support groups, such as for ITP during pregnancy • **Information Sources:** Patients found valuable information through online communities, medical journals, and organizations like the Platelet Disorder Support Association (PDSA) • **Improved Communication:** There is a growing trend towards more patient-friendly discussions in medical journals, enhancing communication and conversations between patients and HCPs » "People [in the support group] are saying doctors are listening to their patients more…Doctors are now listening to symptoms like fatigue. Better discussions are happening between ITP patients and ITP doctors – that's paramount."
	Pediatric caregiver session • **Desire for Peer Connection:** Parents feel isolated and seek support through connections with others experiencing similar challenges. Conferences and support groups are valuable for learning about ITP and connecting with other families. There is also a need to support the whole family unit, such as psychosocial support for siblings • **Information Sources:** Initially, parents depend on HCPs, but later they often turn to resources like the PDSA for additional support and understanding • **Evolving Understanding:** Some parents avoid seeking too much information initially to prevent feeling overwhelmed or scared. Parents gradually become more involved in care decisions as they develop a better understanding of ITP » "We relied on our hematologist a lot because I didn't want to google a lot and get freaked out. They did give us some handouts – a book…We found PDSA later because I didn't want to do too much [at first]. I wanted to be calm for my daughter."

Note. HCP = health-care provider; ITP = immune thrombocytopenia; PDSA = Platelet Disorder Support Association.

☞ *Continued on the next page*

Table 2. Theme-Based Insights From Learning Exchange Sessions: Patient and Caregiver Insights, With Selected Supportive Quotes (cont.)

Theme	Insights
ITP management	*Adult session* • **Collaborative Learning:** Open discussions are important to patients, in part because patients and HCPs are learning together as treatments and knowledge of ITP evolve • **Treatment Journey:** Many patients are made aware of and explore different treatment options, while others are left frustrated by a lack of diverse options being presented, leading to them conducting their own research » "I was getting frustrated when I wasn't getting any other treatment options, and since I have a background in public health, I did some research to determine where research was being done so I would have more treatment options." • **Treatment Evolution:** Patients reported that therapeutic strategies, including choice and timing of different agents, has evolved over the past decade and felt that awareness of how science and treatment approaches change over time is important
	Pediatric caregiver session • **Quality of Life and Normalcy:** Parents desire treatment options that allow their children to have a sense of normalcy • **Trust in Healthcare Team:** Parents initially rely on the recommendations of their care team for what's best for ITP management because they do not yet know anything about the condition » "I think we just 100% put the trust into our hematologist. It was kind of a new thing and they really didn't have a lot of information when [--] was diagnosed. We really just got all of our information from the hematologist and the hospital."
Communication with care team	*Pediatric caregiver session only* • **Misconceptions and Expectations:** Parents may have misconceptions or hope for a quick resolution, impacting their perception of treatments and ongoing care » "We got a little comic book about what ITP is, but we thought it would go away and we were focused on that." • **Chronic ITP and Long-Term Management:** There is a clear need for improved information and education regarding the chronic nature of the condition and its long-term management • **Effective Communication:** A healthcare team that communicates well with both the parent and child is crucial, especially as the child matures and gains more control over their health decisions » "As a teenager, he went straight to 'I want to go on medication because I just want to be normal.' He didn't really need medication, so it was important to have a team that would speak to him in a way that makes sense. It's important to have a team that can be helpful for your child when they can make some of their own decisions, too." • **Navigating Child Aging:** There is a need to understand how to deal with healthcare systems or transition of care once a child has more autonomy over their care management and decision-making. Support and proper communication will be particularly important as young children become teenagers and may demonstrate more resistance to care

Note. HCP = health-care provider; ITP = immune thrombocytopenia; PDSA = Platelet Disorder Support Association.

and remember to assess the overall well-being of their patients and families throughout treatment.

Health-care providers agreed that diagnosis and early care interactions were the ideal times to initiate patient and family involvement in decision-making, encourage self-advocacy on behalf of patients/caregivers, provide support and resource referrals, and begin education according to the needs and preferences of the patients/caregivers. Health-care providers emphasized that patients/caregivers should receive reassurance and information from their care team about the condition, resources such as PDSA, realistic expectations, tips on managing life with ITP, and details on when and how to contact them. While HCP participants emphasized education and shared decision-making as part of their approach to ITP management, multiple patient/caregiver participants had encountered different experiences with their own HCPs, perhaps reflecting the increased desire for education on behalf of the Learning Exchange participants and/or the greater ITP expertise and emphasis on best-practice ITP care on behalf of the participating HCPs. The importance of effective communication, discussions, and collaboration over the course of treatment was especially significant to families with pediatric ITP diagnoses, as the duration of

Table 3. **Theme-Based Insights From Learning Exchange Sessions: HCP Insights, With Selected Supportive Quotes**

Theme	**Insights**
Communication and support	*Adult session* • **Educational Resources:** HCPs stressed the importance of discussing treatment options and providing educational materials to patients to enhance understanding, such as a patient-oriented disease state awareness primer • **Patient Feedback:** Increased patient feedback and communication about treatment goals and side effects are vital for enhancing shared-decision making and improving outcomes » "It would help to have more feedback from patients about what's important to them – more advocacy from the patient side rather than paternalistic support...more communication in the beginning about goals, side effects, etc."
	Pediatric caregiver session • **Early Involvement:** Assessing knowledge of ITP to tailor discussions appropriately and involving families from the beginning helps ensure patients and caregivers are actively involved in decision-making. This is an increasingly important part of the standard of care » "I try to involve the families much more now...I give my opinion on the order of treatments and then I kind of let the patients choose from there. I try to be open from the beginning and then give the thought process of why we're doing this. An open line of communication – involving them in the decision-making at each point – really helps." • **Patient-Centered Communication:** HCPs emphasize understanding patient and family concerns, educating them about ITP, and discussing treatment options openly. Acknowledging and addressing fears is crucial for effective communication and empowering families to participate in decision-making » "Sometimes I have parents who have done some of their own research, sometimes I have patients who don't know what to ask. I always try to explain the patient is healthy, they just have low platelets. But I try to stay away from how long it will last. I try to prepare them that it may not get better, but that we're there to help in any way." • **Resource Utilization:** Clear communication and providing resources, such as the PDSA website, are essential for patient and family education • **Gradual Education:** Educating families gradually helps prevent overwhelming them, while still preparing them for all potential outcomes » "We usually sit down with the families and make sure that they know there are going to be treatment options. We do tell them off the bat that this could be short-term or long-term. The minute you tell them it could be a long-term thing, people tend to get anxious right away. If you give them bits and pieces it allows them time to focus on getting stable for the time being."
Current challenges	*Adult session* • **Knowledge Gaps:** Significant gaps exist in clinical knowledge, particularly regarding comorbidity management, longitudinal and validated disease-specific quality of life measures, treatment sequencing consensus, and diagnostic or treatment-predictive biomarkers » "I think we will all admit there are some gaps in what we know." • **Anticoagulant Management:** Managing patients who require anticoagulants but have low platelet counts presents a clinical challenge that needs to be addressed • **Resource Needs:** HCPs expressed a need for more detailed data and guidance in areas where current knowledge is lacking
	Pediatric caregiver session • **Challenges with Educated Patients:** Educated caregivers can sometimes be challenging for HCPs because they may know more than the HCP about ITP, due to time constraints on the HCP
ITP management	*Pediatric caregiver session only* • **Insurance Challenges:** HCPs often see difficulty with insurance coverage and access to the right treatments • **Holistic Management:** HCPs are increasingly addressing both the physical and psychological aspects of ITP. Reassuring families that serious complications are rare and advising on practical precautions is important for managing concerns » "My approach has always been to get a good understanding of what's really important to the family and how the new diagnosis is impacting or changing things that they have been doing, and then how can we intervene if we need to in order to make sure that whatever the diagnosis is – whether it's temporary or it's longer – that it doesn't really change the person's life." • **Contact Information:** HCPs should ensure families know under what circumstances and how to contact them by providing specific contact details for all involved in the patient's care

Note. HCP = health-care provider; ITP = immune thrombocytopenia; PDSA = Platelet Disorder Support Association.

Table 4. **Theme-Based Insights From Learning Exchange Sessions: Group Insights, With Selected Supportive Quotes**

Theme	Insights
Advocacy and support	*Adult session* • **Self-Advocacy:** Encouraging self-advocacy and peer support is valuable for patients facing similar challenges » "I learned a lot from [--] about advocacy for myself. I wish I had done a better job of self-advocating but it [splenectomy] was so long ago…The past 5 years or so, though, I've had more of a say in my treatment." [Patient] • **Resource Management:** There is a need for improved resources to navigate conflicting diagnoses and to help patients manage complex health issues • **HCP Support:** HCPs can enhance patient experiences by addressing resource challenges and improving support systems, including by utilizing their own professional networks
	Pediatric caregiver session • **Patient Awareness:** Parents/caregivers found it surprising and useful to learn the right times to contact their HCPs » "I don't think our pediatrician told us to call or ask questions – that would have been super helpful to have in the beginning. It would have been nice to know to call if this happens, etc." [Parent] • **Awareness of Resources:** The PDSA organization is appreciated for its support but needs greater visibility, especially in underserved areas » "A lot of families look to Facebook for support and they end up in these family forums…[they] are only going by what is said and are getting subpar treatment. It would be great to get the word out." [HCP] • **Importance of Communication:** Effective communication with HCPs is crucial for patient satisfaction. Clear guidelines are required to help patients determine when to call a doctor for ITP-related issues • **Knowledge and Access Gap:** There is a lack of print information and resources, especially in smaller communities. Enhancing search engine optimization for reliable ITP resources could help families find accurate information online » "As a newly diagnosed patient…you don't always know that you're not getting the best care options. It wasn't until we found PDSA that we realized there are alternatives out there and we could go get a second opinion. Finding the information is hard until you get connected to the right place to get the information." [Parent] • **Mentorship Opportunity:** While no current mentorship programs exist, interest in becoming mentors suggests a potential area for development. Patients stated engaging with others and learning at conferences like PDSA inspired them to seek second opinions and explore improved care options

Note. HCP = health-care provider; ITP = immune thrombocytopenia; PDSA = Platelet Disorder Support Association.

disease has implications for children's important life events, including school, sports, transitioning to adult providers, living independently, choosing a career, and starting a family. Effective transition of care for children with chronic ITP is an important area for future development and may help address the challenges unique to this patient demographic (Jegathesan et al., 2020).

As time with the diagnosis increased and patients/caregivers became more familiar with the condition and treatment options, many felt more comfortable with their level of understanding and felt increasingly confident about their need to self-advocate and even to educate their HCP team on recent research and treatment options. Patients and caregivers emphasized the importance of support from groups like PDSA and from other patients and families who have dealt with ITP. PDSA offers comprehensive educational materials and was the primary resource identified by patients, parents/caregivers, and HCPs as being helpful and informative.

Immune thrombocytopenia guidelines from the American Society of Hematology confirm a lack of evidence for preferred sequencing of treatment options and emphasize the importance of shared decision-making (Neunert et al., 2019). Health-care providers desired more evidence-based guidelines and detailed HCP education resources, while patients/caregivers expressed their desire for open, honest communication with providers as they all advanced their knowledge of ITP

Table 4. Theme-Based Insights From Learning Exchange Sessions: Group Insights, With Selected Supportive Quotes (cont.)

Theme	Insights
ITP management	*Adult session* • **Individualized Treatment:** ITP treatment should be personalized, with patients feeling empowered to make informed decisions about their care » "I loved what I heard from the doctors and the other patients about needing more support and education. ITP may be low platelets, but it's a very individualized experience…not all patients know they can be involved in decision-making and I think that's key. We need to make sure patients feel empowered that they are part of decision-making." [Patient] • **Second Opinions:** Encouraging patients to seek second opinions, particularly at academic centers, should be supported and not seen as a slight by doctors. It may be appropriate to encourage people to do one-time visits at other treatment centers, because there is a disparate amount of information between academic specialists and community doctors • **Knowledge Expansion:** The rapid increase in medical knowledge can overwhelm HCPs; maintaining open communication and utilizing networks can aid in staying informed and up to date with clinical data » "There are magnitudes more to know now and it becomes almost an impossible task to really be up to speed and able to answer everyone's questions. Especially with the wide variety of medical information – so what we do is network ourselves with gurus who may be an expert in particular cases." [HCP]
	Pediatric caregiver session • **Expert Centers:** There was consensus on the need for ITP expert teams or centers nationwide • **Collaborative Network:** Given the complexity of managing ITP, all participants agreed a network of collaborative HCPs is necessary to manage ITP effectively and improve communication, especially as related to pediatricians and hematologists and for children with additional health needs • **Access to Appropriate Treatment:** HCPs and patients often have to navigate insurance-related issues, and insurance is often a barrier to the right treatment
Mental well-being	*Adult session only* • **Mental Health Integration:** Patients with ITP emphasize the need for mental health support alongside physical treatment, feeling that many doctors focus too heavily on lab numbers rather than overall well-being » "It was great to hear [--] say the mental health aspect is so important when treating. My doctor was so 'by the numbers' and didn't really talk to me about how I was feeling or what I was feeling." [Patient] • **Access to Counseling:** High-quality counseling for anxiety is often difficult to access; guidelines should highlight the importance of integrating mental health support into ITP care

Note. HCP = health-care provider; ITP = immune thrombocytopenia; PDSA = Platelet Disorder Support Association.

and the patient's individualized treatment needs together. As patients age, concomitant management of chronic ITP with other chronic comorbidities, such as atrial fibrillation, create further challenges for effective management. Identifying HCPs and/or centers with particular expertise to guide patients and other HCPs could improve care overall. In general, patient, caregiver, and HCP attendees from both sessions agreed on the importance of improving education, resources, communication, and shared decision-making as ways to enrich the patient–provider relationship and enhance the diagnostic and treatment journey for people with ITP.

Despite prompts on the topics of symptom burden, perceptions about ITP misconceptions, quality of life, and changes in treatments/goals over time, patients/caregivers did not spend much time discussing them. Health-care providers likewise gave less attention to prompts regarding key issues in medical management, treatment selection based on patient-specific characteristics, or indications for treatment switching. Because participants were free to discuss whatever they felt was most important to their experiences with ITP, the emphasis on communication, education, and relationship management topics in both sessions suggest these needs are pervasive and significant to patients, caregivers, and HCPs. Notably, opinions and discussions did not differ significantly between MD and advanced practice provider (APP) participants, likely due to the collaborative nature

Table 5. Follow-Up Survey Results on Key Themes From the Learning Exchange

Theme	Total patient/caregiver points allotted[a]	Total physician points allotted
Empowering patients to self-advocate	26	41
Strengthening shared decision-making	26	40
Improving resources and support	21	30
Following the evolving treatment landscape	16	22
Mental health support	16	17

Note. [a]Respondents rated topics by importance from 1 to 5; their topic ranked most important was allotted 5 points, second place received 4 points, third place received 3 points, fourth place received 2 points, and last place received 1 point. Point allotments were tallied from all respondents to generate the total scores for each theme.

of advanced practice teams and evidence showing that the provider role (APP vs. physician) often has less influence on shared-care insights than patient focus and systemic barriers (Martin et al., 2025). The ranked statements in the post-session surveys reinforce the insight that patients/caregivers and HCPs believe empowerment for self-advocacy and shared decision-making are critical to improving the patient and caregiver experience in this disease state.

While these findings offer practical insights for care and education, several limitations should be considered. First, participants were recruited through PDSA, and many had prior advocacy or outreach experience or had attended ITP conferences, which may orient perspectives toward self-advocacy and education and limit generalizability to the broader patient population. Patient and caregiver participants were also predominantly female, which could emphasize themes that differ from those of males living with chronic ITP. In addition, this quality improvement initiative was sponsored by Sobi and reviewed by the company's internal compliance and ethics committees rather than an independent institutional review board; despite efforts to ensure rigor and transparency, sponsor involvement and the absence of external review may introduce bias. As a result, the findings from these Learning Exchange sessions may not be generalizable to all patients, caregivers, HCPs, or care settings. Nevertheless, 4 hours of structured, multi-stakeholder dialogue among 13 patients/caregivers and 14 HCPs yielded rich, patient- and provider-centered insights that are directly actionable for advocacy, education, and quality improvement. Future quantitative and qualitative research or resource development initiatives can take a more focused approach to identifying optimal solutions for the specific unmet needs identified here. Preliminary suggested solutions to these needs are provided in Table 6.

This study's findings can aid caregivers and patients with ITP in recognizing the need to self-advocate to improve their own disease-related education, gain access to the latest treatment options, obtain care related to psychosocial needs, and improve shared decision-making and communication with their care team. Advocacy organizations are a vital part of this process and can support patients throughout the ITP disease and treatment journey. Health-care providers, including APPs, are uniquely positioned to use this study's insights to better understand patient and caregiver experiences, particularly related to diagnosis, nonphysical symptoms, the need for support referrals, and resource-seeking. They can also use the findings to inform their approach to patient and caregiver education and proactive, shared decision-making processes throughout the treatment journey.

The insights revealed through these Learning Exchange sessions offer opportunities to improve the quality of care in ITP, including the experience of diagnosis, treatment, and support of patients with chronic ITP and families through the development of educational materials, identification and promotion of ITP-related support resources, and facilitation of patient and caregiver support

Table 6. **Identified Needs and Practical Solutions for Patients, Families/Caregivers, and HCPs Managing Chronic ITP**

Identified needs and priorities	Proposed solutions
Empowering patients to self-advocate	• Development and distribution of materials for distribution by advocacy groups on topics, including: » How to self-advocate » How to advocate for your child » Understanding your new diagnosis » When to call the doctor » Coping with uncertainty » How to obtain mental health and quality-of-life support
Strengthening shared decision-making	• Development and distribution of key educational resources for distribution by HCPs and advocacy organizations on topics, including: » Questions to ask your ITP doctor » How to engage in shared decision-making » Managing ITP (beyond platelet count) » Treatment options • Training sessions at professional HCP conferences to educate HCPs on how to encourage shared decision-making and patient/family engagement in discussions about chronic ITP management and well-being • Observational studies to examine the impact of shared decision-making on clinical outcomes or satisfaction with care
Improving resources and support	• Development of list of chronic ITP resources and support groups for clinics and advocacy groups to distribute • Advocacy-driven mentoring and training for patients/families • Subpopulation support group development (eg, pediatric ITP, parents with ITP) by advocacy organizations • HCP skills training on shared decision-making and empathetic communication at professional conferences • Development of professional practice tools for identification and referral for common comorbid health needs • Guideline-based practice recommendations for ITP clinicians to improve communication and networking with patients' primary care providers and other specialists as appropriate
Following the evolving treatment landscape	• Professional committee development to explore and document emerging research on knowledge gaps • Quantitative studies to identify practice variation and treatment outcomes • Clinical trials to explore optimal treatment sequencing for patients with different ITP severity and duration • Clinical trials to identify optimal management of cardiovascular comorbidities via anticoagulant use • Development of standards for ITP Centers of Excellence • Routine evaluation and update of ITP treatment guidelines
Mental health support	• Repeated distribution of resource list for support groups and advocacy organizations at diagnosis and follow-up visits • Development and validation of chronic ITP QoL tools • Incorporation of validated QoL tools into ITP clinical trials • Routine clinician inquiry about mental health and QoL » Preidentified referral options for counseling or psychological treatment • Incorporation of QoL/mental health inquiries into best-practice guidelines for clinicians

Note. HCP = health-care provider; ITP = immune thrombocytopenia; QoL = quality of life.

networks. They provide a starting point for further investigation into chronic ITP-related unmet needs and appropriate educational resource development for patient, caregiver, and HCP audiences. This summary of the experiences and perceptions of chronic ITP stakeholders also informs future investigation into the challenges surrounding chronic ITP-related decision-making, optimal care, and patient and caregiver support, education, and communication. ●

Acknowledgment
Funding for the panel activities and manuscript development was provided by Sobi Inc., and Sensified, LLC, provided support for meeting execution, and medical writing. This manuscript was developed by the authors in accordance with Good Publication Practice (GPP) 2022 guidelines (https://www.ismpp.org/gpp-2022). Sobi reviewed and provided feedback on the manuscript. The authors had full editorial control of the manuscript and provided their final approval of all content.

Disclosure

The consensus panel was funded by Sobi, Inc. Participants received compensation for their time. Dr. Tarantino has received consulting fees from Pfizer, Sanofi, Sobi, Takeda, Amgen, Octapharma, Genentech, BioMarin, UCB Biosciences, Dova Pharmaceuticals, and Novo Nordisk; honoraria from Sobi, Genentech, Amgen, Novartis, BioMarin, and Sanofi; and served on advisory boards for Takeda and Octapharma. Mr. Dubinski and Ms. Ferber are employees of Sobi. Dr. Falcon has received honoraria from Sobi. Dr. Foy has received consulting fees from Rigel, Apellis, argenx, Alexion, Pharmacosmos, and Sobi. He has also received honoraria from Rigel and Alexion, and support for attending meetings and/or travel from Pharmacosmos. Ms. Kirk has received honoraria from X4 Pharmaceuticals and BioMarin. She also reports advisory board payments from Sanofi, Hema Biologics, and Sobi, and employment with Sanofi. Dr. Lambert has received consulting fees from Novartis, Dova, Principia, argenx, Rigel, Sobi, Sanofi, and Janssen. Dr. Radulescu has received consulting fees from Sobi, Pfizer, and Sanofi. Dr. Romina Sosa has served on an advisory board for Sobi. The remaining authors have no conflicts of interest to disclose.

References

Cooper, N., Kruse, A., Kruse, C., Watson, S., Morgan, M., Provan, D., Ghanima, W., Arnold, D. M., Tomiyama, Y., Santoro, C., Michel, M., Laborde, S., Lovrencic, B., Hou, M., Bailey, T., Taylor-Stokes, G., Haenig, J., & Bussel, J. B. (2021). Immune thrombocytopenia (ITP) World Impact Survey (I-WISh): Impact of ITP on health-related quality of life. *American Journal of Hematology*, 96(2), 199–207. https://doi.org/10.1002/ajh.26036

Harris, E. M., Hillier, K., Nolan, M., Meleedy-Rey, P., Buissereth, T., & Grace, R. F. (2023). Utilization of an ITP quality improvement pathway improves adherence to management guidelines. *Pediatric Blood & Cancer*, *70*(3), e30074. https://doi.org/10.1002/pbc.30074

Jegathesan, T., Roth, M., Florence, M., Mistry, N., Bonifacio, H. J., Sgro, M., & Baker, J. (2020). 107 A novel transition clinic for adolescents and young adults with non-malignant blood disorders. *Paediatrics & Child Health*, *25*(Suppl 2), e44–e45. https://doi.org/10.1093/pch/pxaa068.106

Kohli, R., & Chaturvedi, S. (2019). Epidemiology and clinical manifestations of immune thrombocytopenia. *Hamostaseologie*, *39*(3), 238–249. https://doi.org/10.1055/s-0039-1683416

Kühne, T., Berchtold, W., Michaels, L. A., Wu, R., Donato, H., Espina, B., Tamary, H., Rodeghiero, F., Chitlur, M., Rischewski, J., Imbach, P., & Intercontinental Cooperative ITP Study Group (2011). Newly diagnosed immune thrombocytopenia in children and adults: a comparative prospective observational registry of the Intercontinental Cooperative Immune Thrombocytopenia Study Group. *Haematologica*, *96*(12), 1831–1837. https://doi.org/10.3324/haematol.2011.050799

Martin, E., Landon, B., Spetz, J., Edgman-Levitan, S., Neprash, H., Bates, D. W., & Rotenstein, L. (2025). An unclear partnership: Key questions about physician and advanced practice provider collaboration in primary care. *Health Affairs Scholar*, *3*(2), qxaf006. https://doi.org/10.1093/haschl/qxaf006

McLinden, D., Myers, S., Seid, M., Busch, M., Davis, D., & Murphy, J. (2019). The Learning Exchange, a Community Knowledge Commons for Learning Networks: Qualitative Evaluation to Test Acceptability, Feasibility, and Utility. *JMIR Formative Research*, *3*(1), e9858. https://doi.org/10.2196/formative.9858

Mier-Alpaño, J. D., Cruz, J. R. B., Fajardo, M. S., Barcena, J. F., Ekblad, E., Hazell, F., Faraon, A. R., Blanco, R. A. T., Gonzales, S., Juban, N., & Labarda, M. (2022). Facilitating learning exchange and building a community of practice to accelerate social innovation in health. *BMJ Innovations*, *8*(3), 155–160. https://doi.org/10.1136/bmjinnov-2021-000882

Neunert, C., Terrell, D. R., Arnold, D. M., Buchanan, G., Cines, D. B., Cooper, N., Cuker, A., Despotovic, J. M., George, J. N., Grace, R. F., Kühne, T., Kuter, D. J., Lim, W., McCrae, K. R., Pruitt, B., Shimanek, H., & Vesely, S. K. (2019). American Society of Hematology 2019 guidelines for immune thrombocytopenia. *Blood Advances*, *3*(23), 3829–3866. https://doi.org/10.1182/bloodadvances.2019000966

Petito, E., & Gresele, P. (2024). Immune attack on megakaryocytes in immune thrombocytopenia. *Research and Practice in Thrombosis and Haemostasis*, *8*(1), 102345. https://doi.org/10.1016/j.rpth.2024.102345

Schifferli, A., Holbro, A., Chitlur, M., Coslovsky, M., Imbach, P., Donato, H., Elalfy, M., Graciela, E., Grainger, J., Holzhauer, S., Riccheri, C., Rodeghiero, F., Ruggeri, M., Tamary, H., Uglova, T., Wu, R., Kühne, T., & Intercontinental Cooperative ITP Study Group (ICIS) (2018). A comparative prospective observational study of children and adults with immune thrombocytopenia: 2-year follow-up. *American Journal of Hematology*, *93*(6), 751–759. https://doi.org/10.1002/ajh.25086

Schultz, C. L., Mitra, N., Schapira, M. M., & Lambert, M. P. (2014). Influence of the American Society of Hematology guidelines on the management of newly diagnosed childhood immune thrombocytopenia. *JAMA Pediatrics, 168*(10), e142214. https://doi.org/10.1001/jamapediatrics.2014.2214

Segal, J. B., & Powe, N. R. (2006). Prevalence of immune thrombocytopenia: Analyses of administrative data. *Journal of Thrombosis and Haemostasis*, *4*(11), 2377–2383. https://doi.org/10.1111/j.1538-7836.2006.02147.x

Shaw, J., Kilpatrick, K., Eisen, M., & Tarantino, M. (2020). The incidence and clinical burden of immune thrombocytopenia in pediatric patients in the United States. *Platelets, 31*(3), 307–314. https://doi.org/10.1080/09537104.2019.1635687

Trotter, P., & Hill, Q. A. (2018). Immune thrombocytopenia: Improving quality of life and patient outcomes. *Patient Related Outcome Measures*, *9*, 369–384. https://doi.org/10.2147/PROM.S140932

U.S. Department of Health and Human Services. (2022). *Immune thrombocytopenia (ITP)*. National Heart Lung and Blood Institute. https://www.nhlbi.nih.gov/health/immune-thrombocytopenia