

AWARENESS

Patient Storytelling – Share Your Story

BEGINNER

→ GATHER AND SHARE POWERFUL STORIES FROM YOUR PATIENT COMMUNITY. THESE STORIES RAISE AWARENESS OF PRIMARY IMMUNODEFICIENCY AND BUILD A STRONGER CONNECTION BETWEEN YOUR ORGANISATION AND YOUR MEMBERS.

OBJECTIVES:

- **Raise Awareness:** Use patient stories to showcase the challenges and successes of living with Primary Immunodeficiency, boosting visibility for your organisation.
- **Build a Community:** Interact with your community, build relationships and encourage members to engage by telling their story.
- **Advocate for your cause:** Use the information you have collected for advocacy.

ADVANTAGES:

- **Engaging Content:** An engagement exercise with your patient community that provides your organisation with interesting content for a variety of uses.
- **Variety of Applications:** Can be used internally for website or newsletters or externally for media, World PI Week or other campaigns to convey a story about your members and organisation.
- **Human Connection:** Personal stories foster empathy and help others understand the lived experiences of people with Primary Immunodeficiency.



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GATHER BASIC INFORMATION

- Collect the **member's name** and ask them to answer: ***“What sparks joy in your life and keeps you going?”***
- Collect a **picture** of the member.
- Get **written consent** to share their information. Template [here](#).

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LET'S LEARN ABOUT THEIR IMMUNODEFICIENCY

- Ask about their **immunodeficiency and diagnosis**.
- Ask them to provide a **personal timeline to diagnosis**.
- Learning **about living with an Immunodeficiency**. Find out how the member manages their condition. Ask:
 - What strategies do they use for day-to-day living?
 - How do they live life to the fullest despite their condition?

REFLECTION

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Ask the member to **reflect on their journey** and **provide some comments** on what they have been through.

CONGRATULATIONS

- After gathering the information, **thank the member for sharing their story**. Send them a copy of their final narrative.
- **Encourage them to continue engaging with your organisation** through events, campaigns, or other storytelling opportunities.

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TIP

- **Be respectful and flexible:** Respect boundaries and let members share as much as they're comfortable with.
- **Use positive framing:** Highlight resilience, joy, and hope while acknowledging Primary Immunodeficiency challenges.