This report represents International Pemphigus Foundation's responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

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Mission:
The mission of the International Pemphigus & Pemphigoid Foundation (IPPF) is to improve the quality of life for all people affected by pemphigus and pemphigoid through early diagnosis and support. The IPPF's most important objectives are to provide patients and doctors worldwide with information about pemphigus and pemphigoid, and to provide patients and their caregivers much needed comfort and support so they can continue to live active, productive lives. To help fulfill those objectives, we: - Offer a physician referral service to help patients find the best medical care possible; - Provide a number of valuable and popular patient support services; - Publish informational brochures, pamphlets and a quarterly newsletter with news, useful information, medical updates, personal stories and more; - Run an annual Patient/Doctor meeting; - Collaborate with pharmaceutical companies on the leading edge of treating these diseases; - Provide up-to-date information about current cl...
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1. What are we aiming to accomplish?
Looking to the future, the IPPF has identified six strategic goals: Reduce diagnostic delays of pemphigus and pemphigoid patients by increasing P/P awareness; Provide high-quality, targeted programs and services that improve the quality of life of those affected by P/P; Support P/P research to increase and improve treatment options and access; Support advocacy efforts that benefit both the P/P community, and the larger rare disease community; Secure the human and physical resources necessary to meet organizational goals and operational plans; Secure funding to sustain or expand current, and implement new, programs and services.

2. What are our strategies for making this happen?
To achieve our goals, the IPPF will: Engage in media and marketing strategy to facilitate increased recognition and diagnosis of PV/MMP; Send Patient Educators to a minimum of 19 U.S. dental schools to provide a personal testimonial and emotional appeal in order to reinforce the importance of considering PV/MMP in their clinical differential diagnosis; Provide expert-led conference calls to increase disease and treatment knowledge; Host a Patient Conference with key opinion leaders and local experts to increase disease, treatment, and lifestyle knowledge; Develop a Comprehensive Disease Profile to guide all patient support efforts; Play an active role in every current pemphigus or pemphigoid clinical trial; Launch an improved P/P Registry; Influence P/P favorable legislation by creating advocacy networks; Ensure current HR capacity supports future needs; Identify a collection of diverse funding sources; Develop plans and budgets for new or expanding programs and services. These, among many other objectives, are part of a new and expanding IPPF initiatives to continue to be the world's leading source of pemphigus and pemphigoid support and information.

3. What are our organization's capabilities for doing this?
The IPPF has identified the strengths and weaknesses of the organization. The IPPF's strengths include a dedicated staff and successful patient support and outreach programs. The weaknesses include fundraising, IPPF awareness, synergy between staff/BOD/MAB, and program measurement. The external factors affecting the IPPF are opportunities and threats. The IPPF's opportunities include enhanced fundraising, advancing research, expanded outreach and support, and developing partnerships. The IPPF also faces several threats to its sustainability and growth: failure to meet stakeholder needs and insufficient funding. To guide our decision making processes, the IPPF operates under four new strategic areas. These four areas ensure the IPPF focuses on its historical areas of service: awareness, advocacy, education, support, and research. These four new strategic areas are: Increase Disease Awareness; Provide Responsible Programming; Advance Treatment and Care; and Strengthen the Organization.

4. How will we know if we're making progress?
The IPPF is establishing an evaluation program that will measure operational effectiveness through weekly, monthly, and quarterly reporting. These measurements currently track target to actual fundraising and program goals to actual.

5. What have and haven't we accomplished so far?
The IPPF is in the early stages of designing a new, more robust patient registry to track a patient's disease, treatment, and quality of life over time. An astonishing 97% of patients said they are willing to provide quarterly or annual updates so the information is rich with data researchers can use to better manage P/P patient care.