



INTERNATIONAL PEMPHIGUS & PEMPHIGOID FOUNDATION

The International Pemphigus & Pemphigoid Foundation (IPPF) is dedicated to improving the quality of life for all people diagnosed with, or affected by, pemphigus or pemphigoid. Pemphigus and pemphigoid (P/P) are rare, autoimmune, blistering diseases affecting the skin and/or mucous membranes. The IPPF provides support services to thousands of P/P patients, caregivers, and medical and dental professionals around the world.

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PEMPHIGUS & PEMPHIGOID AWARENESS

PUT IT ON YOUR RADAR

INTERNATIONAL PEMPHIGUS & PEMPHIGOID FOUNDATION
AWARENESS CAMPAIGN

IPPF AWARENESS CAMPAIGN

The IPPF Awareness Campaign seeks to reduce the amount of time it takes a patient to receive a pemphigus vulgaris (PV) or mucous membrane pemphigoid (MMP) diagnosis. The average pemphigus or pemphigoid (P/P) patient sees five doctors over ten months in search of a diagnosis. Since the majority of P/P patients present oral symptoms first, the Awareness Campaign focuses on PV and MMP—two forms of P/P with increased presentation in the mouth. PV/MMP patients often see a dentist as one of their first clinician contacts. Therefore, outreach is directed at dental professionals, given their unique opportunity to shorten diagnosis times.

AWARENESS CAMPAIGN GOALS

By January 2017, PV/MMP patients will report:

- A decrease in the average number of healthcare professionals seen to receive a PV/MMP diagnosis.
- A decrease in the months taken to receive a PV/MMP diagnosis.



The Awareness Campaign is funded by the Sy Syms Foundation and the Unger family.

THE ROLE

OF THE DENTIST

General dentists have the unique opportunity to shorten diagnosis times by recognizing PV/MMP symptoms and referring patients to a dentist or dental specialist experienced in performing biopsies of vesiculobullous lesions. Dentists could reduce a patient's uncertainty and anxiety by confidently educating a patient about PV/MMP and reassuring the patient that effective treatments exist.

OF THE DENTAL SPECIALIST

It is common for patients to first see a dentist and then be referred to a dental specialist, such as a periodontist or oral surgeon. It is important for specialists to be well-versed in performing biopsies of vesiculobullous lesions.

OF THE DENTAL HYGIENIST

Because of their direct relationship with patients, dental hygienists play an important role in the IPPF Awareness Campaign by providing proper care in dental maintenance to PV/MMP patients, spreading awareness, and sharing key symptom recognition messages with other oral health care providers.

DENTAL PROFESSIONALS SHOULD
INTRODUCE EVERY PATIENT WITH
PV/MMP TO THE IPPF.



DIAGNOSTIC PATHWAY DATA

In October 2011, the IPPF conducted an independent study of 87 pemphigus and pemphigoid patients to identify their diagnostic pathway.

- Almost 80% of patients sought medical attention within the first three months of symptom onset. The majority (63.2%) of patients' initial symptoms were lesions in and/or on the mouth, lip, gums, or throat. Dentists were one of the top clinicians seen first, with 23% of patients seeing a dentist as their first clinician.
- On average, patients saw five doctors in pursuit of a correct diagnosis, and 10% reported seeing more than 10 health care providers.
- On average, it took patients 10 months to achieve a correct diagnosis.
- More than half of patients reported extreme difficulty in finding a doctor knowledgeable enough to accurately diagnose (56%) and effectively treat (51.2%) their condition.
- Of patients who saw a dentist (n=52), 46% said their dentist was not knowledgeable about P/P symptoms and performed no action relevant to P/P. Forty percent were referred to another healthcare provider, and 13% received a diagnosis.
- The majority (83%) of patients reported having a negative experience when seeking a diagnosis.
- More than half (60.1%) of patients felt the time it took them to be diagnosed was too long.
- Almost all patients (96.6%) were unaware of P/P prior to their diagnosis.
- When asked to indicate the one emotion that best described their experience from the time symptoms appeared to receiving an accurate diagnosis, 49.4% of patients said "frustrated;" 18.4% said "anxious;" and 11.5% said "confused." Only 1.1% said "satisfied."

EDUCATIONAL OPPORTUNITIES

FOR DENTAL PROFESSIONALS

The IPPF provides continuing education (CE) opportunities for dental professionals across the United States. Providers will have the option to attend in-person or online CE courses.

Contact awareness@pemphigus.org to learn about opportunities near you.

FOR DENTAL STUDENTS

To increase retention of PV/MMP curriculum, IPPF Patient Educators will visit a minimum of 19 U.S. dental schools. Patient Educators share their diagnosis stories and provide an emotional appeal to dental students. The lecture begins with a short video on PV/MMP, followed by a Patient Educator presentation and Q&A session. These lectures are easily incorporated into standard class times.



Becky Strong, an IPPF Patient Educator, talks about her pathway to a pemphigus diagnosis in an IPPF educational video.