



## 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.

### CONNECT WITH US!

Facebook.com/HealOurSkin  
Twitter.com/HealOurSkin  
Instagram.com/HealOurSkin

Use #healourskin, #PutItOnYourRadar, #pemphigus, #pemphigoid, #ippf

**Address | Contact Information**  
1331 Garden Highway, Suite 100  
Sacramento, CA 95833

T: (855) 4-PEMPHIGUS  
T: (916) 922-1298  
F: (916) 922-1458

E: awareness@pemphigus.org  
W: www.pemphigus.org/awareness

**Subscribe**  
www.pemphigus.org/awareness/subscribe



PUT IT ON YOUR RADAR

## 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.

INTERNATIONAL PEMPHIGUS & PEMPHIGOID FOUNDATION

AWARENESS CAMPAIGN



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.

---

On average,  
it takes a patient  
**10 months**  
to obtain a correct  
diagnosis.

## 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](mailto: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.