Keynote Presentation: A Nurse’s Personal Perspective - Pemphigus / Pemphigoid and the Eye

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Financial Disclosures

Pemphigus vs. Pemphigoid

Courtesy of Grant Anhalt
Johns Hopkins University

Courtesy of Kim Yancy
University of Texas Southwestern - Dallas

Courtesy of Kin Yancey
University of Texas Southwestern - Dallas
Direct Immunofluorescence

About Me

Becky’s Story
- Diagnosed in 2010 with PV
- 17 months to get a diagnosis and 6 different doctors
- Symptoms - every mucous membrane affected and skin
- Oral treatment only, off label
- Complications of treatments
Treatments

- Prednisone
- Mycophenolate mofetil
- Clobetasol cream

PATIENT SUPPORT SERVICES

- Physician Referral List
- Peer Health Coaches
- Patient Education Calls
- Support Group Meetings
- Quarterly Newsletter
- Annual Patient Education Conference

www.pemphigus.org
RESOURCES FOR PROFESSIONALS

- CE courses
- Patient speakers
- Educational materials
- Comprehensive disease information

www.PutItOnYourRadar.org

About Marc

Marc’s Story

- Diagnosed in 2007 w/ MMP
- 5 Months & 5 Physicians to get Diagnosed
- Symptoms: Vision loss, Mouth, Nasal Cavity, esophagus, skin, and genital area
- Multidisciplinary approach needed
- Multiple treatment failures, Off-Label drugs needed for remission
Marc’s Story

- Symptoms: eyes, nose mouth, nasal cavity, esophagus, skin and genital area
- Eye involvement
  - Red, itchy eye
  - Conjunctivitis
  - Discharge
  - Photophobia
  - “Gritty” feeling

Marc’s Health

- Treatments
  - High Dose Prednisone
  - Dapsone
  - Imuran
  - IVIG
  - Cyclophosphamide
  - Rituximab
- Side Effects
  - Diabetes/High Blood Sugar
  - Anemia
  - Fatigue
  - Suppressed Immune System
  - Pneumonia
  - Mood Swings
  - Cataracts
  - Muscle/Joint Aches

Ophthalmology Considerations

- Skin Lesions
- Compromised Immune System
- Electrolyte Imbalance
- Comorbidities
- Surgical Considerations
- Anesthesia issues
Key Points

- YOU have the unique role in reducing patient diagnostic delays.
- It is okay not to know; but keep searching until you get your patient an answer.
- Consider rare diseases when assessing patients with oral lesions, and remember the importance of a diagnostic biopsy.
- There is a whole patient wrapped around the mouth. Compassion is key!

Additional Information

International Pemphigus & Pemphigoid Foundation
Awareness Program
PutItOnYourRadar.org

Contact the Awareness Program
• awareness@pemphigus.org

Contact Me
• becky@pemphigus.org