

# THE GLOBAL VITILIGO FOUNDATION

Richard H. Huggins, M.D

Vicki Tiahrt



# RICHARD H. HUGGINS, MD

- Dermatologist at Henry Ford Hospital specializing in vitiligo
- V Strong Vitiligo Support Community - Medical Advisor
- Global Vitiligo Foundation – Board of Directors and GVF-C Chairman



# VICKI TIAHRT

- **Vitiligan**
- **Experienced vitiligo advocate**
- **Global Vitiligo Foundation – Patient Co-Chair**



# GLOBAL VITILIGO FOUNDATION

- International physician- and patient-led group of individuals working together to help find better treatments and a cure for vitiligo
- Established in 2011
- Producers of “Vitiligo: Truth, Hope and Change” video



# GVF BOARD OF DIRECTORS

- **Iltefat H. Hamzavi, M.D. (GVF Medical Co-Chair)- Henry Ford Hospital, Hamzavi Dermatology (Detroit, MI)**
- **Henry W. Lim, M.D. - Henry Ford Hospital (Detroit, MI)**
- **Pearl Grimes, M.D. - The Vitiligo & Pigmentation Institute of Southern California (Los Angeles, California)**
- **Amit G. Pandya, M.D. (WVD HOUSTON CONFERENCE MEDICAL CHAIR!)- University of Texas Southwestern Medical Center (Dallas, Texas)**
- **John H. Harris, M.D., Ph.D. - University of Massachusetts Medical School (Worcester, MA)**
- **Kim Boyd - Comerica Bank (Detroit, MI)**



# globalvitiligofoundation.org

The screenshot shows a web browser window with the URL <https://www.globalvitiligofoundation.org/publications>. The page features a dark header with the GVF logo and the text "Global Vitiligo Foundation" on the left, and a "Login/Sign up" link on the right. A horizontal navigation menu includes the following items: ABOUT US, Events, ABOUT VITILIGO, RESEARCH, MEDIA, ADVOCACY, SPONSORS, RESOURCES, PHYSICIANS ONLY, and DONATE. The "ABOUT VITILIGO" item is highlighted, and a dropdown menu is visible with the following options: About Vitiligo, Types of Vitiligo, Treatments, Vitiligo Facts, Camouflage, Mental Health, and Dietary. Below the navigation menu, the word "Publications" is visible on the left side of the page.



# INTERNATIONAL VITILIGO MANAGEMENT GUIDELINES

- Many members of the GVF are part of an international group of vitiligo experts working together to develop vitiligo management guidelines that will be made available for patients and physicians around the world
- Expected to be completed by sometime next year



# GVF AND VITILIGO PATIENTS

- The GVF fully values and supports the efforts of vitiligo patients and local support groups
- Direct financial support to local support groups
- Financial support for patients attending national and international meetings and advocacy events
- Patient curriculum for Vitiligo International Symposium in Detroit in 2018





# GVF AND US-WVD

- **GVF recognizes the value WVD brings to the entire vitiligo global community.**
- **Main financial sponsor of WVD Houston 2019 and has supported every US national WVD celebration, starting with the 2016 Rally in Washington, DC (Valarie Molyneux)**



# GVF AND US-WVD

- **GVF is increasing its commitment to the US-WVD Conference going forward.**
  - **Pledging to serve as the primary support structure and primary fundraiser from now on.**
  - **Still wants patients to remain at the forefront in organizing them**



# PHARMACEUTICAL SPONSORS

- **Pharmaceutical companies are invaluable allies in our war against vitiligo and many have been great supporters of the GVF**
- **These include Incyte Corporation, Tevodo Biodevices, Everbowl and Temprian Pharmaceuticals**



# PHARMACEUTICAL SPONSORS

- **Incyte – main pharmaceutical sponsor for WVD Houston 2019**
  - **Genuine interest in supporting the GVF and vitiligo patients in general**
  - **created their own patient advocacy division**
  - **Asking for patient volunteers to do brief interviews about their experiences with vitiligo for social media (in front of the “Rock the skin you’re in” sign in the hallway)**
  - **Look for one of the representatives from Incyte**



# PATIENT-PHARMA SESSION

- Opportunity to speak directly to pharmaceutical sponsors today from 5:30-6:30PM
- The purposes of the session
  - Pharmaceutical industry representative introductions
  - Learn more about individuals with vitiligo and the vitiligo support groups
  - Try to better incorporate the patients in drug development
  - Learn how they can best support the vitiligo patient community
- All who are able are encouraged to attend

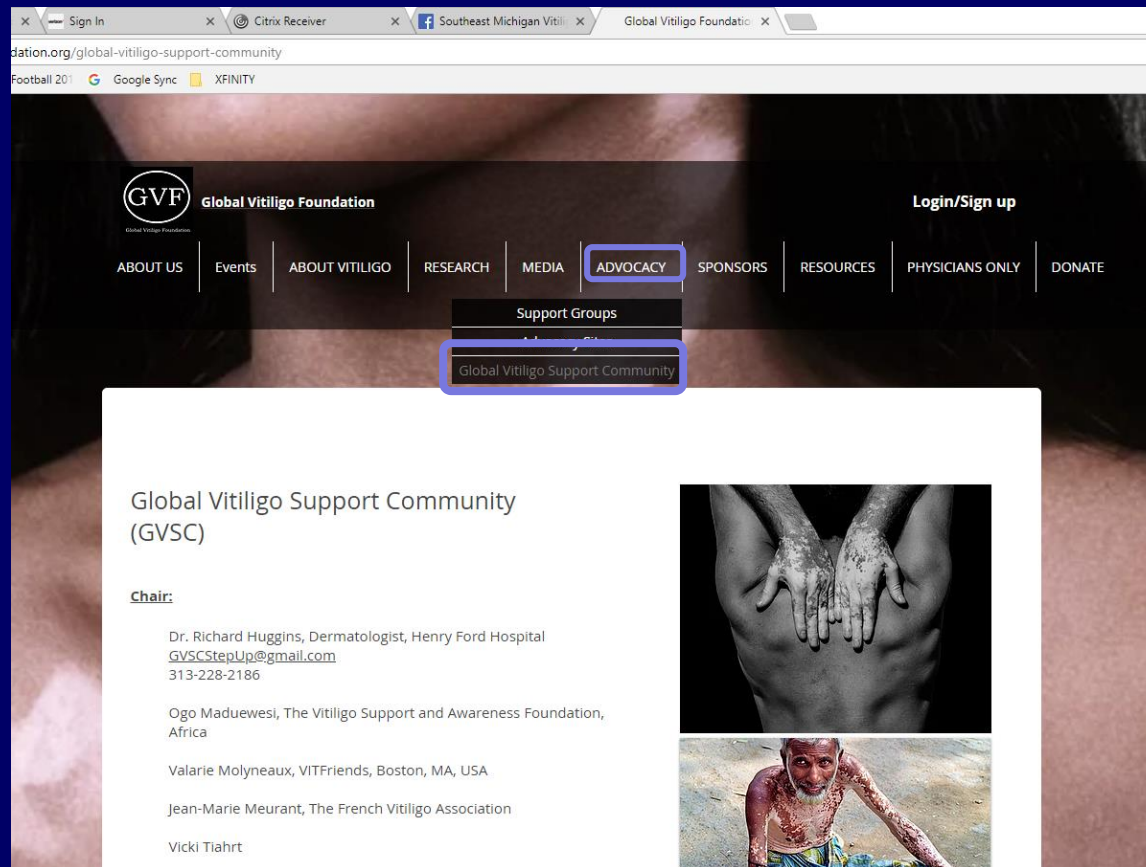


# GLOBAL VITILIGO FOUNDATION - COMMUNITY

- GVF-C formerly know as the Global Vitiligo Support Community (GVSC)
- Patient support section of the GVF
- Objectives
  - Support Group Collaboration
  - Connect Patient/Support Groups to the medical community (GVF)
- National > International
- >25 member groups ([gvsctestup@gmail.com](mailto:gvsctestup@gmail.com))



# globalvitiligofoundation.org/global-vitiligo-support-community

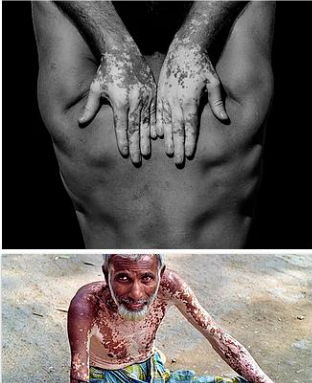


The screenshot shows a web browser window with the URL [globalvitiligofoundation.org/global-vitiligo-support-community](http://globalvitiligofoundation.org/global-vitiligo-support-community). The page features a dark header with the GVF logo and navigation links. The 'ADVOCACY' link is highlighted, and a dropdown menu shows 'Support Groups' with 'Global Vitiligo Support Community' selected. The main content area displays the title 'Global Vitiligo Support Community (GVSC)' and a list of chairs.

**Global Vitiligo Support Community (GVSC)**

**Chair:**

- Dr. Richard Huggins, Dermatologist, Henry Ford Hospital  
[GVSCStepUp@gmail.com](mailto:GVSCStepUp@gmail.com)  
313-228-2186
- Ogo Maduewesi, The Vitiligo Support and Awareness Foundation, Africa
- Valarie Molyneaux, VITFriends, Boston, MA, USA
- Jean-Marie Meurant, The French Vitiligo Association
- Vicki Tiaht



# SUPPORT GROUP DIRECTORY

The screenshot shows the website for the Global Vitiligo Foundation (GVF). The navigation menu includes: ABOUT US, Events, ABOUT VITILIGO, RESEARCH, MEDIA, ADVOCACY, SPONSORS, RESOURCES, PHYSICIANS ONLY, and DONATE. The 'ADVOCACY' menu item is highlighted, and a sub-menu is open showing 'Support Groups', 'Advocacy Sites', and 'Global Vitiligo Support Community'. The 'Support Groups' sub-menu item is also highlighted.

## Support Groups

Support groups are a valuable resource to help people deal with the impact that vitiligo has on their lives. They provide a safe environment to share emotions and have discussions with people dealing with many of the same issues. Below are some support groups:

- California
  - Los Angeles, CA, USA: Vitiligo Support/Los Angeles, California
    - <https://www.facebook.com/groups/713605405393631>
  - Orange County, CA USA: Orange County Support Group
    - <http://www.ocvitiligosupport.com/>
    - <https://www.facebook.com/OCVitiligoSupport>
    - [OC Support Group April Meeting Flyer](#)
- Connecticut
  - Hartford, CT, USA: VITFriends
    - <http://www.vitfriends.com/>
- Delaware
  - Dover, DE, USA - Delaware Vitiligo Support and Awareness Group (DVSAG)
    - [https://www.facebook.com/groups/209736308676?ref=br\\_rs](https://www.facebook.com/groups/209736308676?ref=br_rs)

**Donate**

The top photograph shows a person's hands with white patches of vitiligo. The bottom photograph shows a person with extensive white patches of vitiligo on their face and torso.





# OPEN TELECONFERENCES

- **Quarterly**
- **Updates regarding activities of various vitiligo support organizations on the call (inspiration and collaboration)**
- **Discussion of issues of mutual concern (i.e. advocacy and WVD)**
- **Minutes disseminated for those who cannot join the call**



# NATIONAL ADVOCACY

- Partnering with Congress to spread vitiligo awareness and raise funds for vitiligo research
- Group Effort
  - VITFriends Legislative Team
    - Wallace Henry, III, EdD
    - Tiffany Grant
  - Dr. Seemal Desai
  - Vicki Tiahr
  - Many others



# NATIONAL ADVOCACY

- Working with Congressman Hank Johnson to help get his resolution for a “National Vitiligo Awareness Day” (H.Res.213) passed



# GVF-Student Allies

- Med students who have volunteered to assist vitiligo support organizations across the country
- Connected 17 med students with 14 vitiligo support group organizations
- Let us know if you have a support group and would like to be connected with a student
- We are working on connecting all interested support groups with physicians as well



# THE SPIRIT OF THE GVF-C



# THE SPIRIT OF THE GVF-C

- **Delaware dermatology office**
  - **Initially refused to allow a vitiligo patient to hang a flyer advertising her support group in their office**
  - **Social media pressure and phone calls from the vitiligo community forced the office to have a change of heart**



# THE SPIRIT OF THE GVF-C

- A patient came to see Dr. John Harris recently and was told by his insurance that the office visit was not covered because he was seen for vitiligo
- Tufts Commercial Health Plan in MA
- Dr. Harris has brought this to light and is working with other members of the vitiligo patient community to have this policy reversed



# THE SPIRIT OF THE GVF-C

- Please join us in letting Tufts Commercial Healthplan of MA know that this is unacceptable
  - 617-972-9400
  - [tuftshealthplan.com](http://tuftshealthplan.com)
  - Facebook, facebook messenger, twitter: @tuftshealthplan (#tuftsignoresvtiligo)





# VITILIGO: TRUTH, HOPE & CHANGE



**THANK YOU!**

**Dr. Rich - [rhuggin1@hfhs.org](mailto:rhuggin1@hfhs.org) or  
[GVSCstepup@gmail.com](mailto:GVSCstepup@gmail.com)**

**Vicki Tiaht - [vlht@hotmail.com](mailto:vlht@hotmail.com)**

