

To mark **Hemochromatosis Awareness Month** 2014 we asked visitors to the Facebook **Fighting Hemochromatosis** page to let us know if they had a GOOD hemochromatosis doctor. We were pleased to get scores of responses and so present the first edition of the "good hemochromatosis doctor" list, dubbed **Hemo-Doc-Stars**.

85 doctors made the list as of July 25, 2014. The list will be updated from time to time as new recommendations come in. Please see the notes and disclaimer at the end of the list for details of why the list was assembled and by whom. We also listed some resources. Note that the numbering on the list is not a ranking, it just helps to count the entries, which we compiled roughly in the order received. Some comments were edited for grammar and clarity.

- 1. Dr. Michael Cannon, Troy MI. Gastrointestinal Specialists, PC.
- 2. Dr. Oscar Signori in Dearborn MI. Part of Oakwood hospital system.
- 3. Dr. Jennifer Trottman, Tulsa, OK. She has been wonderful!
- 4. My doctor is Dr. Stephen Janney, Comprehensive Cancer, St. Louis, MO. Kudos to the entire practice...all of them are wonderful and so patient with me.
- 5. Shout out also to the awesome doctor who diagnosed me in Nashville, TN, Dr. Robert Bishop, at Southern Hills Medical Center. Dr. Bishop is in family practice and noticed elevated iron in some blood work and probably saved my life.
- 6. Dr. Pezzimenti. Danbury, CT.
- 7. Dr. Perkovic in Varazdin, Croatia, but I doubt this info could help anyone from USA.
- 8. Dr. Kowley Hematologists/Liver Specialist/oncologists, Seattle, WA.
- 9. Center for Cancer and Blood Disorders, Dr. Ralph Boccia and Victor Priego in Bethesda, MD. Also Alison Moliterno, MD at Johns Hopkins University Medical Center, Baltimore, MD.
- 10. Digestive Health Associates, 4100 Park Forest Drive, Suite 208, Traverse City, MI. The specialist I see is Jeffrey Goldman, M.D., F.A.C.G., A.G.A.F.
- 11. Dr. Medd In Westbrook, ME (General Practitioner.) And Dr. Morse, Portland Gastroenterology, in Portland, ME. Dr. Morse Specializes in Hereditary Hemochromatosis.
- 12. Dr. valentine, Calgary, Alberta, Canada.
- 13. Dr. Rebecca Barrington, Kerrville, Texas.
- 14. Dr. Bishop, Prince George, British Columbia, Canada.

- 15. Dr. George, Oncologist, Geneva, IL.
- 16. Dr. Rodriguez, College Station, TX (Scott and White).
- 17. Dr. McFarland at the Cancer Specialist of the Rockies in Fort Collins, CO.
- 18. Dr. David Molthrop, Orlando, Florida.
- 19. Dr. S. Smiley and the Gals @ Katmai Oncology Group, Anchorage, AK.
- 20. Dr. Neveling, General practitioner. Dawson Creek, BC, Canada.
- 21. Glenn Baker, MD, Kaiser Permanente, Aurora, CO.
- 22. Dr. LIDDLE at Lexington Clinic in Lexington, KY.
- 23. Dr. Aparna Hernandez in Orlando, FL.
- 24. Dr. Caroline Behler in San Francisco.
- 25. Dr. Wieder, New Hyde Park, New York.
- 26. Dr. Hals in Lake Worth, Texas.
- 27. Omid Shaye MD, Los Angeles area.
- 28. Dr. Jey Maran in Gainesville, VA.
- 29. Dr. Scott Christianson at UC Davis, Rocklin, CA. He was my doctor for 12 years. Love him!
- 30. Dr. Raul Alverez @ Colorado Blood & Cancer Care, Denver, CO.
- 31. Dr. Sean Cunningham, Des Moines, IA.
- 32. Dr. Michael Pokarier, Bracken Ridge, Brisbane, Australia. He listens.
- 33. Dr. Patel. Tri-city Cancer center Kennewick, WA.
- 34. Dr. Gavin Hui at Milton Hospital, Milton, Ontario, Canada.
- 35. Dr. Kelli Fox, found it, then sent me to Dr. Spivey for further testing at Texas Oncology Denton, TX.
- 36. Dr. Leo Zacharski, Dartmouth Hitchcock Medical Center, Lebanon, New Hampshire.
- 37. Dr. Mazengiya, Mount Gambier, South Australia.
- 38. Dr. Bruce Bacon in St Louis MO. Awesome! He gets it.
- 39. IMS Hematology and Oncology, Tempe, AZ. Dr. Robin Obenchain. Awesome and extremely knowledgeable doctor! Please visit her in Phoenix, Chandler, Tempe, Mesa, Gilbert!
- 40. Dr. Miriam Atkins from Augusta, GA. She is my hematologist at Augusta Oncology Associates. She is great!
- 41. Dr. Dow, Greenway Surgery, Wirral, England, UK.
- 42. Gastroenterologist Dr. Chen at Kaiser San Jose.
- 43. Dr. Yu, Gastro at Casco Bay Gastroenterology, South Portland, Maine...love this man!

- 44. Dr. Novick, Digestive Specialist Dayton, Ohio.
- 45. Dr. Edwin Kingsley (Comprehensive Cancer Centers) in Las Vegas & Dr. Robert Levy of Connecticut Oncology Group in CT wonderful!
- 46. The Best in Orange County, CA, is Dr. Steven Kim.
- 47. Dr. Jason Chandler, West Clinic, Memphis, TN.
- 48. Dr. William G Martin, SCMC Cancer Center Bend, Oregon, 97701.
- 49. Dr. Ravi, Eastside Hematology & Oncology, North Hills Medical Center, Greenville, SC.
- 50. Dr. Puppala, whereever he now works is my hero...very well mannered and intelligent.
- 51. Dr. Neimkin (retired?) in Asheville, NC. He diagnosed me three weeks after wrist surgery. He had been diagnosed several years earlier in his shoulder.
- 52. Dr. Alejandro Calvo, Hematology/Oncology in Dayton, Ohio.
- 53. Dr. Jeffrey Hancock, hematologist/oncologist at Teton Oncology in Idaho Falls, Idaho.
- 54. THE BEST: Dr. Richard Hellman Waterford, CT hematologist oncologist specialist at the new state-of-the-art Dana-Farber Cancer Center.
- 55. Dr. Morey Blinder, St. Louis, MO
- 56. Dr. J. Rooney, Reliant Medical, Worcester, MA.
- 57. Dr.Stuart Gold, hematologist oncologist, and Dr.Litchman, gastroenterologist. Both at UNC Chapel Hill.
- 58. Dr. Paul Whiting, director of clinical pathology, Capital Pathology, Canberra, Australia.
- 59. Dr. Brad Baltz in Little Rock, AR. Hematologist / Oncologist.
- 60. My gastroenterologist is Doctor Barry Slitsky, Springfield, MA. He is a Wonderful doctor.
- 61. Amazingly, my cardiologist diagnosed me since I had seriously high calcium levels. He referred me to Dr. VanDana Sharma in Fremont, CA. She's an oncologist/hematologist.
- 62. Dr. Owen Pickus, Portland Maine.
- 63. Dr. Joseph Mikhael at Mayo Clinic, Scottsdale, AZ.
- 64. Dr. Sharma, Riverhead, NY hematology and oncology the office is wonderful.
- 65. Dr. Rachel Harper, Lexington Clinic, Lexington Kentucky. I drive over 100 miles one way to get to her.
- 66. Dr. Ajay Dar, Virginia Cancer Specialists, Northern VA.
- 67. Dr. Waits in Evansville, Indiana.
- 68. Dr. Cawley in Marietta, OH, is awesome.
- 69. Dr. Rubenstein, San Jose, CA. He sees many patients with Hemochromatosis and even has special needles and bags for giving blood. The staff is excellent! I never get poked more than once.

- 70. Clinic 7 at Lincoln County Hospital, Lincoln, UK. Fab doctor!
- 71. Dr. Edwin Kingsley, Las Vegas, NV.
- 72. The whole team at Bronglais Hospital, Aberystwyth, Wales.
- 73. Dr. Gwynn, Haematologist (and all the knowledgable nurses in the clinic), at Crawley Hospital, West Sussex. England.
- 74. Dr. B Thompson, Church Place, Lurgan, Co Armagh, Northern Ireland.
- 75. Dr. Grant at Leicester General Hospital.
- 76. Dr. Babak Khanzadi, Jimboomba, Queensland, Australia.
- 77. Dr. Barton at Brookwood Hospital in Birmingham, AL.
- 78. Dr. Delcambre (formally Dr. Haines) at Children's Hospital in Birmingham, AL.
- 79. Dr. Shweta Adya, Internal Medicine, Aurora, Indiana 47001. This doctor has stood by me for two years now since my diagnosis...a doctor that cares, listens and obviously did the research on my Genetic Hemochromatosis that it takes to treat and continue to treat my disease. I recommend Dr. Shweta Adya to any Hemochromatosis sufferer 1000%!!!
- 80. Dr. Arthur Poch, Gastro, Shreveport, LA.
- 81. Dr. Stolpman, St Louis Park, MN. Gastroenterologist. Hands down fantastic. Affiliated with Park Nicollet Clinic, Methodist Hospital.
- 82. Doctor Troy Schmit, Sanford Clinic, Sioux Falls, South Dakota.
- 83. Dr. Robert Alter, Hackensack, NJ.
- 84. Dr. Jones, St John's Hospital, Livingston, West Lothian, Scotland. Explains everything. Staff in the Haematology Day Bed Unit are also great.
- 85. Dr. Shaelinder Pottumutho, Narooma, NSW, Australia.

Notes and disclaimers: The names and comments in this list were volunteered for publication by people from around the world who are struggling with hemochromatosis, in response to a question posed on the Fighting Hemochromatosis page on Facebook: Has anyone got a GOOD hemochromatosis doctor? The names of patients making the recommendations were removed in the interests of medical privacy.

We rely on the good faith of members of the hemochromatosis community to provide good information to us, but we cannot vouch for or substantiate any of the data in this list and disclaim any responsibility for any actions that anyone takes based on the information in this list. We can say that the names were supplied by members of the public, not by doctors. We should add that this list was prepared by volunteers, working on their own time, in the hopes of helping others, and not by any part of the medical community, which on the whole seems to care very little about the most prevalent genetic killer in America today, hereditary hemochromatosis.

What's the thinking behind this list? Many people who encounter hemochromatosis complain about poor treatment by doctors and clinics. This ranges from ignorance to rudeness to outright malpractice. In fact, a study by America's Centers for Disease Control and Prevention found that, on average, it took a staggering 9.5 years from symptom onset for a patient to be diagnosed with hemochromatosis (that's enough time to kill or cripple a person whose body is rapidly loading excess iron). At first, we thought that naming and shaming bad doctors might help improve things, but on reflection we decided that it was much better to try and raise the bar by recognizing those doctors who treat this condition with the appropriate care and concern, the hemochromatosis rock stars.

If you see errors in the list or have additional recommendations please email sc at celticcurse dot org. In the future we hope to make a list of recommended blood centers that know how to properly handle blood donated by hemochromatosis sufferers. And if this all goes well, we will try to put the information into a state-by-state format that can be referenced online.

Hemochromatosis Resources:

- The <u>Iron Disorders Institute</u> is the best place to turn for a full range of medically reviewed information about hemochromatosis. The good folks at IDI have been working for many years to educate doctors and nurses and patients about hemochromatosis. We also heartily recommend their books: <u>The IDI Guide to Hemochromatosis</u> and <u>The Hemochromatosis Cook Book</u>.
- There is a great documentary called <u>Iron Men</u>, which helps you understand the condition and the way it impacts families.
- The Canadian Hemochromatosis Society.
- Haemochromatosis Australia.
- The UK Haemochromatosis Society.
- The Irish Haemochromatosis Society.