

MEET THE IMF HOTLINE COORDINATORS

The IMF Hotline 800-452-CURE (2873) is staffed by Debbie Birns, Paul Hewitt, and Nancy Baxter. The phone lines are open Monday through Friday, 8am to 4pm (Pacific Time). To submit your question online, please email TheIMF@myeloma.org.

How did you become an IMF Hotline Coordinator?

Nancy Baxter: After practicing law for five years, I became a mother and no longer wanted to work full-time. So I trained as a psycho-social cancer counselor at UCLA (University of California Los Angeles), and went to work part-time at UCLA's Jonsson Comprehensive Cancer Center (JCCC). Two years later, UCLA became one of the National Cancer Institute (NCI) Cancer Information Service centers, and I was asked to supervise a staff of 15 phone counselors. That's when I recruited Debbie Birns to join our team.

All of us received advanced training from the NCI. In 1999, when the NCI consolidated its California call centers and closed the UCLA office, I became a patient services manager at the Leukemia & Lymphoma Society (LLS). In 2001, I met IMF president Susie Novis at an outreach event. She was interviewing candidates for the IMF hotline, and I recommended Debbie for the position.

Debbie Birns: I was an undergraduate major in humanities and English literature. I spent most of my sophomore year in Florence, which is where I learned Italian. I completed two and a half years of a PhD program in comparative literature when I had my first child and became a stay-at-home mom. When the youngest of my three children was a toddler, I went back to UCLA to study professional writing and editing, and became a manuscript editor for the UC Press. During the 1980s, several members of my immediate family were diagnosed with cancer, including my mother-in-law, who had myeloma. Near the end of her illness in 1992, Nancy recruited me for the NCI Cancer Information Service at UCLA. After the program closed, I went to work at UCLA's Clinical Research Unit under Dr. Dennis Slamon, whose prior work led to the development of the breast cancer drug Herceptin[®]. I learned a great deal about cancer clinical trials there, but the job entailed only limited aspects of my training and experience. Then Nancy called to tell me about the IMF.

Nancy Baxter: Once Debbie shared with me the impressions of her new job at the IMF, I realized how much I missed working directly with patients and family members. Two months later, I joined the IMF Hotline.

Paul Hewitt: My background is as an actor. After a long run in a Broadway show in New York, I returned to Los Angeles, where Susie Novis and I live on the same street. We would meet while walking our dogs, and we'd chat and catch up. That's how I originally came to work for the IMF. A couple of years later, when the IMF was ready to add a third coordinator to its Hotline, Nancy and Debbie approached me about joining the department. After six months of intensive training, I was ready to field calls.

What is it like to work on the IMF Hotline?

Paul: Our callers are thirsty for knowledge. Helping them address the various aspects of myeloma in a more informed way is incredibly fulfilling.

Nancy: This is the best job I've ever had. I've received incredible training from the most extraordinary doctors. I work with wonderful people. I've gotten to know many amazing patients and caregivers. I have witnessed myeloma treatments evolve from being primarily transplant-based to a



Hotline staff: Debbie Birns, Paul Hewitt, and Nancy Baxter

broad range of novel therapies that have improved patients' survival and quality of life. I have seen first-hand how informed patients are able to make more educated decisions about their treatment options and how the patients' feedback about various therapies and side effects has impacted doctors' approaches to dosing and clinical trial design. The IMF Hotline is a unique asset in the dynamic relationship between the patient and medical communities.

Debbie: Working for the IMF has brought together and called upon everything I have ever studied or done professionally, or experienced in my personal life. It is the most fulfilling work I have ever done. I treasure the interaction with patients and caregivers, as well as the intellectual stimulation of having the most accomplished clinicians and researchers as my teachers and mentors.

Each of you has a sub-specialty. What is it?

Debbie: Because of my research background, I track myeloma clinical trials for the Myeloma Matrix. I also work with IMF Board member Mike Katz in conducting video interviews with myeloma specialists at the annual meetings of the American Society of Hematology (ASH) for posting on our website, and I edit the IMF's educational materials.

Nancy: In between taking Hotline calls and answering emails, I am involved in outreach. I make sure that information about the IMF and myeloma gets out not only to the major cancer centers across the United States but also to smaller, community-based doctors.

Paul: My sub-specialty is to coordinate the participant registration aspects of the IMF Patient & Family Seminar program.

What should prospective callers know about the IMF Hotline?

Debbie: Perhaps one of the most surprising and useful aspects of the IMF Hotline is that none of the coordinators are medical professionals. We are not doctors or nurses. We are people who have been trained to translate the most sophisticated science into terms that are accessible to our callers, and to make information about a very complicated cancer and its treatments readily available. Patients and their advocates must have the facts in order to communicate well with the healthcare team. Our take-home message to patients and their loved ones is "KNOWLEDGE IS POWER."

Paul: We learn the latest developments in the field of myeloma from the specialists who are actively working on putting an end to this disease, and this enables us to better serve our callers. And, if a patient or family member is outside the United States and cannot get in touch with us by phone, I want them to know that we welcome their letters and emails.

Nancy: We understand the issues that myeloma patients and caregivers tackle. We are here to help answer their questions, and to help frame the questions that they need to pose to their healthcare providers in order to have a more productive dialogue. I look forward to going to work in the morning so that I may serve the members of the myeloma community who face each day of their lives with humor, courage, strength, dignity, and hope. **MT**