

## Lighting a Candle Grassroots efforts for oral chemotherapy access in Wisconsin

BY PARAMESWARAN HARI, MD, MRCP, MS



*It is better to light a candle than curse the darkness — John F. Kennedy*

It was in 2007 that a patient of mine (Jane) called my office requesting that we not reorder her chemotherapy—even though it was working very well for her relapsed myeloma. Often, when patients ask to stop effective treatment, it is because of worries about the side effects of long-term therapy or chronic side effects. So I called Jane back and confirmed that she was tolerating treatment very well and experiencing no negative side effects. Her husband (Roger) finally told me that they simply could not afford the co-pay each month for her oral medication (lenalidomide) and there was no way they could refill the script. So they decided to take a chance on the myeloma staying inactive. Roger had a good job and their employer-based insurance was generally characterized as “good” insurance by our clinic’s financial coordinators.

### The Elephant in the Room

That experience was the first time I understood the financial challenges that newer oral chemotherapy drugs created for patients. Lenalidomide was new to the market at the time and it was considered by Jane’s insurance as a regular prescription medication just like routine anti-hypertensives, for example. After several phone calls and many conversations with payers, I had a grasp of this problem—which, in fact, was now starting to affect patients with hematological malignancies in a major way.

Oral chemotherapy medications are

revolutionizing oncology and converting diseases like myeloma into chronic illnesses. In addition to effectiveness, oral medications are more convenient, generate fewer office visits, and are more suitable for people who can continue to stay productive and active in society. However, our payment models seemed stuck in a past era where infusional chemotherapy was considered a medical benefit and reimbursed fully by payers and oral drugs—chemotherapy or otherwise—were covered by prescription coverage and entailed a system of co-pays and out-of-pocket costs, sometimes with no annual cap.

### Addressing the Issue through Oral Parity Legislation

Fortunately, patient support groups across the country were hearing the same complaint and a movement was taking shape across several states. The oral chemotherapy parity movement sought to establish equivalency in payment for anti-cancer medications whether they were administered in IV or in pill form.

I was privileged to be part of this movement in my home state of Wisconsin. Starting in 2008 to 2009, we mobilized a coalition of patient support groups, disease-specific charities, hospitals,



On April 2, 2014, Wisconsin Governor Scott Walker signed the Cancer Treatment Fairness Act into law at the Froedtert and Medical College of Wisconsin.

oncologists, and patients to educate our state legislature about the issue and support passage of an oral chemotherapy parity law.

Early on we made several phone calls to influential state legislators who raised awareness about the issue and brought SB300 (Senate Bill 300) to the floor of the Wisconsin legislature. We had committee hearings, followed by public hearings, and years passed before we could rejoice in the passage of the oral parity bill.

Although Wisconsin was one of the states to get an early start on this initiative, the passage of oral parity legislation took five years and a lot of struggle.

### It Takes a Village

As with most physicians, politics and activism were new territories for me. I needed considerable help from my patients, various societies, such as the Leukemia & Lymphoma Society, the International Myeloma Foundation, and many others, to navigate these uncharted seas. While I did not believe we would run into opposition, in a democracy there are always opposing viewpoints and our state legislators needed convincing. I quickly learned that what seems obvious, ethical, and beneficial from one's own viewpoint is not always the perspective shared by others.

Our grassroots effort had some close misses; there was also turnover in the state legislature during this period. Groups opposed to the bill felt that its passage would bring forth a mandate and they opposed passage within the broader context of healthcare reform that was happening across the country at the same time.

Our strategy was to keep up the public pressure and continually point out the benefits of the legislation. We were able to do so with newspaper articles featuring patient testimony, op-ed pieces, stories on television news channels, and radio programs. Using all of these venues, we were able to keep our side of the argument in front of the public.

My role was to be available and to articulate the argument for oral chemotherapy parity. Several of my patients who were finding it difficult to afford oral chemotherapy prescriptions shared their stories in the media. Working in partnership, providers and patients participated in the public hearings at the state Capitol.

The sense of camaraderie between



In 2014 Dr. Hari received a grassroots advocacy award at ACCC's Annual National Meeting in Arlington, Va. Pictured (left to right) are the 2014 Oncology Grassroots Champion for Patient Access Award recipients: James Thomas, MD, PhD, Medical College of Wisconsin; Seija Olivier, RN, Allegiance Health, Jackson, Mich.; Parameswaran Hari, MD, MRCP, MS, Medical College of Wisconsin; and Matt Sherer, MBA, MHA, Tallahassee Memorial Cancer Center, Tallahassee, Fla.

patients, caregivers, and healthcare professionals and the emotional high of being able to meaningfully impact lives was the greatest reward for all of us involved in this grassroots effort.

### Thanks for the Support

I must thank a number of people for their support; individuals and organizations that allowed and encouraged my participation. My employer, the Medical College of Wisconsin and its office of Public Affairs were helpful each step of the way. Our hospital partner, Froedtert Hospital, formed a coalition of like-minded hospitals in Wisconsin to support our grassroots effort for oral parity legislation.

The efforts of patient support groups—especially the Leukemia & Lymphoma Society and the International Myeloma Foundation—was crucial as they assumed a liaison function between the various stakeholders.


### Parting Words

For colleagues who are engaged in similar efforts, I offer this advice: stay engaged and listen to your patients as to what can be done beyond medicine to help them through their cancer journey. Luckily, I believe that most hospitals and medical practices are open to their clinicians spending time on such efforts.

Media engagement is also critical. Although I will admit that it takes practice

to learn how to put one's viewpoint across succinctly during media interviews. In the future, social media will also be important in generating buzz around causes.

For us, April 2, 2014, was the day that the Governor of Wisconsin, Scott Walker, finally signed the bill into law. The signing was held at my hospital and in the presence of numerous patients, families, hospital representatives, legislators, and representatives from patient support groups and hospital systems. The venue was chosen in recognition of the efforts we had put in and it made the victory even sweeter.

Looking back, I learned much about the inner workings of our democratic government and what it takes to get legislation passed—even when the issue has bipartisan support. I now have a deeper appreciation of the fight our cancer patients and their caregivers and supporters have to go through. I know that putting together a coalition of people committed to a cause needs time, emotional energy, and patience. But when the cause is right and when victory is won—there is no greater satisfaction. 

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