The Chronic Myelogenous Leukemia Society of Canada
La Société de la Leucemie Myéloide chronique du Canada

Special Report

ASH 2011

SPARKS OF LIFE – Margot Miller

Descending toward Calgary, on my way to ASH 2011, the morning was still dark and as I looked out my window I saw "sparks" flying by. It took me a moment to realize it was snowing. Thousands of beautifully illuminated snowflakes whizzed past the plane window. It was a stunning foreshadowing of the beautiful, brilliant experience and knowledge presented at ASH.

ASH is a gathering of nations. It is a coming together of the CML world. Scientists, doctors, researchers and patient advocates attend this conference from all corners of the globe.

CML does not discriminate. CML knows no age, no country, no religion, no colour, and no economic status.

We are blood brothers and sisters, united through a disease most of us had never heard of before being diagnosed with CML.

> The four-letter word, CURE is spoken more frequently.

ASH is a beautiful event because doctors, scientists, researchers and patient advocates are all there for the betterment of the lives of CML patients. It is encouraging to see and hear how many people are dedicated to solving the puzzle that is Chronic Myeloid Leukemia.

Presentations on various aspects of CML research, showed this writer that getting an answer to the CML puzzle is not like peering into a clear crystal ball, but more like peering into a faceted crystal ball, where there are brilliant refractions leading to a broader spectrum of knowledge. The facets of CML are being revealed more every day.

The STIM II Trials, which are clinical stop trial studies, are showing some promising results. Fifty percent of patients on this trial need to return to drug therapy within 6 months, but the majority regains their previous response within several months. The other 50% remain treatment free and PCRU at 2 years. The researchers are learning so much about the characteristics of CML, both from the patients that have to resume therapy and up to this point, those patients who do not.

All stop trial patients must meet strict criteria to qualify for the trial and are monitored closely with monthly PCR's.

Floating in the air of the ASH conference 2011 was a detectable feeling of hope towards a cure.

On Monday afternoon, Dr. Janet Rowley and Dr. Brian Druker were honoured. Dr. Rowley discovered the chromosomal translocation known as the Philadelphia Chromosome, which then led to the development of Gleevec, the targeted therapy, which was discovered by Dr. Brian Druker. The session was called "Chronic Myeloid Leukemia (CML): A Success Story from Chromosomes to Effective Therapy". Dr. Rowley is a dynamic woman, who is 86 years young. She spoke with humour, energy and great knowledge. In a taped interview with Cheryl-Anne Simoneau, President of the CML Society of Canada, Dr. Rowley expressed that "as a Physician; meeting patients who have responded to treatment for 10 or more years is an enormous pleasure and wouldn't have been possible before". Dr. Rowley has inspired a new generation of CML researchers and it is good to know that she herself is still an active researcher.

Dr. Brian Druker discovered Gleevec. He persisted in his research against heavy skepticism and significant odds. Dr. Druker is a very caring, humble man, dedicated to his patients. In his talk he stated that the direction of future CML research is to "distinguish Leukemic stem cells from normal stem cells and work towards eradicating them". When congratulated by Cheryl-Anne on his award, he said, "his greatest reward is seeing patients well".

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As patients we know that after the shock of being diagnosed, it can be hard to get a confident footing in life again. Even if treatment is going very well, there can be a feeling of waiting for the other shoe to drop.

What I can share with you from ASH is that the stop trials show good promise for some patients. There are drugs in the pipeline to address mutations that have not responded to present therapies. Many aspects of CML are being researched.

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There is recognition that while the majority of CML patients are doing well (though not without side effects) there are some who are not. The presentations and posters at ASH confirmed that CML research is continuing at a fast pace. The four-letter word, CURE is spoken more frequently.

To all Canadian CML patients, and to all patients worldwide, may you have a long and healthy life! This wish, this hope seems entirely possible after hearing from many who are dedicated to this goal.

Let the sparks continue to fly.

Margot Miller
CML Prairies Patient Representative

Taking the Pulse at ASH – Sandy Shaw

Having just returned from my first ASH meeting and as the newest Board member of the CML Society of Canada, I must say how impressed I am with the dedication of the researchers, physicians, patient advocates and manufacturers involved in the diagnosis, treatment and management of CML as observed at the 2011 ASH conference. I was indeed fortunate to hear the two 'heavy weights' of CML, Dr. Rowley (discoverer of the 9-22 translocation responsible for CML) and Dr. Druker (who persisted with research into imatinib to treat the disease, against significant odds), give keynote speeches outlining the arduous paths to their discoveries. Dr. Rowley and Dr. Druker were awarded the Ernest Beutler Lecture and Prize at this conference for their lifetime investments in translational advances in a single area. Their presentations were delivered to a packed conference room that held thousands of seats, underlining the importance of their work in this field to all areas of hematology and hematologic cancers.

> CML is being touted as the poster child of cancers – a relatively rare disease whose secrets are expected to be unlocked, and thus lead to the better management and possible cure of many more cancers.

The CML Society of Canada was privileged to interview both physicians,(please see the video clips on our website) and hear that they believe a cure is possible within the near future for some patients and within the not too distant future for many more. What an accomplishment for a disease that only a little more than a decade ago carried such a poor prognosis! Each day of the conference was packed with activities from early morning to late night. We attended presentations by researchers on issues related to new and existing CML drug treatments, basic science on new CML drugs and disease genetics and novel approaches to potential future management. We reviewed all of the scientific posters on CML and queried the authors on their significance. We secured meetings to discuss mutually beneficial partnerships with manufacturers of currently available agents, manufacturers of drugs filing for approval or in clinical trials and manufacturers involved in monitoring BCR-AB. We met with top international and Canadian CML specialists regarding specific treatment challenges. We forged and cemented collaborative friendships with CML advocacy groups from other countries

> I was struck with how generous everyone was with his or her time and advice. Their commitment to helping achieve a cure for CML was palpable.

My only disappointment was the lack of presence by politicians and government bureaucrats involved in healthcare allocation, especially from Canada. Jordan's health minister, whom we briefly met in the exhibitor area, was a notable exception.

I perceived a notable shift from concentration on treatment options to a less tentative emphasis on a possible cure. Not that choice in treatments is not important. We urgently need more drugs available to treat those who fail currently available TKIs either because of intolerance, poor quality of life or resistance. We need more sensitive means for detecting residual BCR ABL loads amongst patients who have achieved $CMR^{4.5}$. A better understanding of the reasons behind less than optimal adherence to drug therapy should to be further explored with means devised to overcome this challenge. Better side effect recognition, reporting and management are also needed.

More efficient and more sensitive mutation profiling (which exists) must be made more accessible.

Nevertheless, several presentations focused on the results of drug cessation in CML patient's undetectable BCR ABL levels (based on CMR $^{4.5}$) shown to be stable over long periods of time with. About 40% of appropriately selected patients are showing a long duration of remission in studies to date, suggestive of 'cure'.

I encourage you to read the updates from ASH contained herein and to watch the interviews for a better understanding of the implications of the research presented.

Finally, I wish you and yours all the best of this holiday season and the best of health for 2012.

Sandra Shaw,
Executive Director

Video Interviews

We are very grateful to Dr. Brian Druker, Dr. Janet Rowley Dr. Susan Branford and Dr. Francois Mahon for being so generous with their time and providing us an interview opportunity.

Please visit our website using the link below to see the video of the interviews.

The video's were produced, scripted, filmed and edited by the entire reporting team of The CML Society of Canada, Mr. Stewart Sklar, Ms. Sandra Shaw, Mrs. Cheryl-Anne Simoneau, and Mrs. Margot Miller.

http://cmlsociety.org/ash-2011-links-to-video-interviews/

We are on the right track! – Cheryl-Anne Simoneau

The news from this year's ASH was probably the most positive we have seen since the excitement that was created by the ASH 2000 meeting and the results of the first Gleevec trials. In contrast to 2000, this year we heard the word CURE, and more than once. From the CML Educational session on Saturday (repeated on Sunday) , we learned about the importance of getting the patient on the right drugs to improve their response, and the important role compliancy to treatment plays for patients. Monitoring patient's response to therapy so that you can spot the occurrence of resistance helps the disease to be better managed in line with a chronic condition. However, Monday December 12th was an exhilarating day with wall-to-wall coverage of CML starting at 10:30 AM right through to the end of the poster session around 8:00 PM. The morning session including discussions and strategies as a result of clinical trial findings that were reported such as closer monitoring so that patients can be rapidly switched to Nilotinib to achieve better rates of overall response, and update on the ENESTnd 36 month trial.

Junia Melo finished up the session with looking at how the future landscape for CML is changing and that the new goal of therapy may in fact be to help most patients achieve the best response possible so that they may be potential candidates for stopping trials of the future.

These two trials show clearly that with closer monitoring we can make sure patients get the right drug at the right time to improve their overall rates of molecular remission. The Gimema (Italian) group of CML experts presented information on combining Imatinib with Nilotinib in an alternating scenario such as using Nilotinib twice daily on alternate days and using Gleevec 400mg on other days. This could be a potentially good scenario when Gleevec becomes generic in most countries and could help patients and governments safely address the economic challenges of paying for these treatments. The BELA trial update regarding Bosutinib was also encouraging as we see with longer data patients tolerate the drug quite well and achieve better response rates. The French Spirit trial confirms that Pegylated Interferon at a dose of 45µg per week in combination with 400mg of Imatinib is the recommended initial dose for patients in CP CML.

In all of these sessions it was interesting to note that CML specialists from around the world are on the path to seeing how to use the newer drugs to help more patients achieve the best response possible.

Ash was as always, exhilarating, informative, and most of all motivating.

Cheryl-Anne Simoneau,
President, Founder,

This newsletter was written, produced and edited by the ASH reporting team of The CML Society of Canada, Mr. Stewart Sklar, Ms. Sandra Shaw, Mrs. Cheryl-Anne Simoneau and Mrs. Margot Miller.