Volume 2 / Issue 1 **February 2009**

CML InterAction

THE OFFICIAL NEWSLETTER
OF **THE CML SOCIETY OF CANADA**

The CML Patients Support and Guidance Organization

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Contents

Presidents Word

Welcome to our second edition of the newsletter for the Society. We've been busy working on this issue to provide more help and advice on "Living Well with CML".

Over all the CML Society has been quite busy since we last published, browsing through our newsletter will give you an idea of some of our activities. We've hosted Pan Canadian focus groups, conducted a web survey and we were invited to be part of a special panel at the American Society of Hematology Satellite Symposium in San Francisco in early December.

We have two new columns for this issue. Thanks to nutritionist Anne Haine for providing us with a column on nutrition. If you have a favorite recipe that is healthy and nutritious, please share it with us. Patient Advisory Board member, Margot Miller asked us to provide her with a list of our favorite books, music videos, and sport activities that has provided us with inspiration along the journey. We are going to continue this list in upcoming editions, so if you have a favorite book, video, movie, music or activity that helps you along your own personal journey, please write to us and let us know, we will make sure it makes it to the list. If you have a favorite recipe that is healthy and nutritious, please share it with us.

The "Patients Voice" feature is the story in "his own words" of a very special fellow CMLer, although I would have to admit that we all are special in our own right. Rav is in his mid twenties and he talks about the special concerns for patients in this age group.

Last winter, one of our patient advisory board members, Cam Williams went into blast crisis. Unfortunately, after two transplants, Cam succumbed to blast crisis CML. This was a painful reminder to all of us that although there have been significant advances in this disease, there are still some patients for whom all treatments fail.

We wish to say thank you to everyone who has helped us this past year. It has been a year of significant growth and opportunity for us to reach out and meet fellow patients across Canada.

Stay Healthy and safe and visit our website often, we will be sharing lots of news as we continue to reach out to each of you.

Love, Kindness and Peace,
Cheryl-Anne Simoneau, President,
The CML Society of Canada

We dedicate this edition of our Newsletter
to the memory of Cameron Wade Williams,
Husband, Father, Son, Uncle, Teacher and dedicated
Patient Advisory Board Member of the
Chronic Myelogenous Leukemia Society of Canada.
Cam's passing reminds us all that
CML is still a very formidable disease.

Some of our favorite things:

The members of the patient's advisory board started a list of our favorite things. Here is a sampling of some of our favorite books, movies, music and other ways to enjoy our time. We are thinking about making this a permanent column. Do you have a favorite thing? Write to us and tell us and we will include it in our next edition. In the spirit of living well with CML, ENJOY!!!

BOOKS

At The Will Of The Body
Arthur W. Frank
A Fine Balance
Rohinton Mistry *(fiction)*
The Makers Diet – Jordan Rubin
The Kite Runner
Kaled Hosseini *(fiction)*
A Thousand Splendid Suns
Kaled Hosseini *(fiction)*
Einstein – **His Life and The Universe** – Walter Isaacson
Its Not About The Bike
My Journey Back To Life
Lance Armstrong
Animal, Vegetable, Miracle
Barbara Kingsolver
The Universe in a Single Atom, The convergence of Science and Spirituality
His Holiness The Dalai Lama
Anti Cancer, A new Way of Life
David Servan Schreiber, M.D, Ph.D

T.V Documentary

Crazy Sexy Cancer – Kris Carr
Planet Earth – BBC, **Young@Heart**

Movies

Hairspray – a non-stop stage smile
Freedom Writers
Bend it Like Beckham
Benny and Joon
Slum Dog Millionaire
Pay it Forward
Mama Mia

Dick and Ricky Hoyt
The Last Lecture – Randy Pausch
Christian The Lion

C.D

Dave Mc Kenna – JAZZ
(any solo piano)
Van Morrison – Moon Dance
Joe Lovana – Sax-Sinatra Album
Miles Davis – Kind of Blue
(the Ultimate Desert Island disc)
Soundtrack from "Across The Universe"
Stir It Up – **Bob Marley and the Wailers**
Nessum Dorma – **Luciano Pavrotti**
Canadian Blues – **Steve Strongman**
How Blue can you get
Soundtrack from Mama Mia

Moving our Bodies

Swimming
SCUBA diving
Snorkelling
Skating
Walking
Running
Working out with a personal trainer
Snowboarding

Places we go

Arivat, Nunavat to visit
Grandchildren
Whistler
California
Chicago
The Cayman Islands
India
Our home Provinces

LEARNING WITH PATIENTS WITH OTHER DISEASES

It was an honor for me to represent the CML Society of Canada at a special meeting in Frankfurt Germany for CML and GIST (Gastro Intestinal Stromal Tumors) Patient group Support leaders. The two and half day event was co-created by European CML Group Leaders as well as Leaders in GIST and sponsored by Novartis Oncology. The agenda was packed with presentations that covered a diverse range of topics and offered updates on some innovative treatments in clinical trials in Europe from two top CML experts, Dr. Eduardo Olavarria and Dr. Andreas Hochhaus. Dr. Olavarria's article regarding his innovative approach to mini SCT's combined with the use of targeted agents immediately following transplant will be published shortly in Blood. We hope that Dr. Hochhaus' innovative approach to combining Gleevec and Interferon will be published soon too. Both approaches to treatment offer alternatives for long-term sustainable drug free remission, which would be warmly welcomed by many of us.

However, it was a presentation from a GIST patient that evoked a floodgate of emotions for me. Marina Symcox was diagnosed with GIST while she was quite young and her family was still much in need of their mother and wife. Unfortunately at the time there was not much to offer GIST patients. In January 2000 Marina's battle was nearly over as she checked herself into a Hospice never expecting to recover. But her husband never gave up and searching the internet he found out about the GIST trials for STI 571 (Gleevec). By October 2000 she had made a full recovery.

Marina has given us permission to post her presentation on our website and I include some insightful tidbits that Marina provided for us:

Mourning What is Lost

"You eke out your illness…only you will love it"

"All of my old trivial selves fell away, and I was reduced to essence." (Anatole Broyard)

Mourning is an affirmation of the life that has been led.

Avoid those who seek to minimize what you have lost.

Loss of: freedom to plan, continuity with your past and your body, some relationships, connection to cultural mainstream, innocence about your mortality. "Sinking all the way through, and discovering a life on the other side." (Arthur Frank)

The Remission Society & Valuing Illness

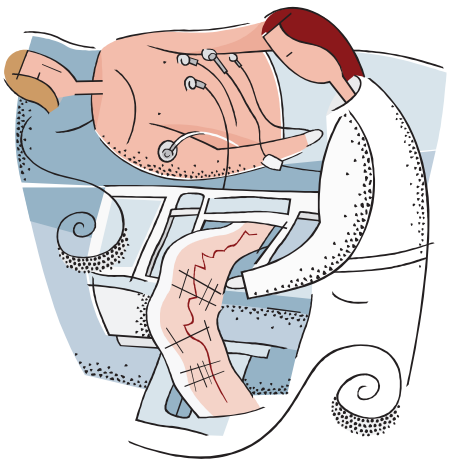
"Wellness and sickness perpetually alternate as foreground and background…
In health there can only be fear of illness, and in illness there is only discontent at not being healthy.

In recovery I see not health but a word that has no opposite...Gravy." (Arthur Frank)

For Marina's full presentation and a short Bio, please visit our website.

Thank you Marina for your kind generosity in sharing with us your pain and helping us define and cope with ours.

Cheers,



HEALTHY LIVING
NUTRITIONAL CHOICES

OHealthy Living – Nutrition guidance
A Haine - Nutritionist

The best pieces of advice and wisdom are those that can be applied not to just one situation but to many aspects of your life. Whether you're dealing with job, children, finances, health, or relationships, nothing is more effective than remembering to keep it simple. It's quite surprising how much we can become unknowingly invested, both physically and emotionally in "white noise" activities and thoughts. Once we pare that away and get to the heart of the matter, we are dealing with what is really necessary without getting lost in what isn't.

This simple rule of thumb can be applied just as easily to eating well. One of the greatest misconceptions surrounding nutrition and healthy eating is that it's difficult, time consuming, and requires heavy research and study before a person can begin to get it right. Nothing could be further from the truth. In actual fact, eating well is very simple.

Our bodies have an innate sense of what we need. Unfortunately, many of us have become deaf to these needs that are in fact being very clearly communicated, if we'd only stop and listen. Think of foods which are consumed due to convenience or advertising allure but which in fact have very little to no nutritional value as the "white noise" of nutrition. This melee of unhealthy products includes processed snack foods, sugary fruit drinks, sweetened cereals, and even some pre-made frozen entrees. Once these products have been edited from your diet, what is left? In most cases, there will be a relatively small quantity of natural foods. These are the foods that warrant your attention and focus, as they are the choices that will provide the most nutrition and the least artificial ingredients of all.

Natural foods are loosely defined as foods grown on fertile soil under natural conditions, or animals raised in natural conditions and ideally, consumed in their natural state. The vitamins and minerals inherent in natural foods are found in very specific combinations, designed to facilitate our absorption of these nutrients. It is fair to say that we are biologically equipped to reap maximum nutrient value from our natural food supply. These foods contain more protein, more vitamins, minerals, and enzymes than processed foods. Simply strive to have these foods as part of each meal daily in order to get maximum nutritional benefit from every bite, without the unnecessary additives, preservatives and potentially unhealthy residues found in processed foods.

In addition to the distraction generated by the wide assortment of processed foods available, is the confusion generated by the promotion of ever changing diets and eating trends. Conflicting information runs rampant. Recent trends have run the gamut from high carbohydrate/low protein eating to recommendations of low carbohydrate/ high protein consumption. These patterns of eating tend to enjoy short-lived popularity and as a rule get lots of publicity from both the media and the corporate members of the food industry whose best interests are being served. Good nutrition is not usually reflected in the nutritional profile of these diets

The simple fact is that food is fuel for our bodies. Protein, carbohydrate, and fat are the three forms in which this fuel is found in foods. Carbohydrates and proteins provide 4 calories of energy per gram and fats provide 9 calories of energy per gram. Our bodies require fuel from all three of these sources in order to run smoothly and efficiently. Essentially, a healthy diet is one in which each calorie provides maximum nutrition in the form of vitamins, minerals, and enzymes. Calories without nutritional benefit are known as "empty calories" and are simply filler calories.

When making choices, you should try to eat a variety of foods from all of the food groups every day. Here are the basics:

Healthy protein sources such as lean meats, fish, poultry, soy, nuts, and seeds.

Green and brightly coloured vegetables and fruits.

Whole grain breads, cereals, and pastas

Dairy products or other foods with calcium such as cheese, yogurt, or milk.

A small amount of healthy fats from nuts, seeds, and oils such as walnut and olive oil.

Combining foods from these groups into simple delicious recipes is easy. When you are cooking with fresh, unadulterated foods in their natural state, the taste is unparalleled and you will find that few ingredients are necessary. Here is an easy and very tasty recipe for pasta with fresh tomato sauce that allows the true taste of the ingredients to shine.

Pasta with Fresh Tomato Sauce:

4 small campari or plum tomatoes, quartered

2 tbsp olive oil

3 tbsp balsamic vinegar

Fresh ground pepper

Sprinkle of kosher or sea salt

Whole grain pasta

Fresh grated parmesan cheese

Fresh basil leaves

Heat olive oil on medium heat. Add quartered tomatoes. Cover and simmer for 3-5 minutes, until tomatoes are softened. Remove lid and add vinegar. Continue to simmer until juices have reduced by half. Remove from heat and season with fresh pepper and salt.

Cook whole grain pasta according to package directions and drain.

Toss sauce with whole grain pasta. Sprinkle with fresh parmesan cheese and chopped fresh basil.

Eating well is not difficult; but it is a conscious choice. We have absolute control over what we decide to put into our bodies. Fortunately, we live in a country where fresh produce, good quality grains, and fresh meat and dairy products are readily available year round. Becoming familiar with which foods pack the biggest punch, nutritionally, gives us the opportunity to provide ourselves with the best quality fuel possible. Simply take the time to stop and listen to your body and then choose wisely.

THE PATIENTS VOICE

Rav

WHAT IF?

Depression, bad case of paranoia, the way your heart races when your doctor phones to say he has your latest PCR results- these are all the nagging psychological side effects of CML Doctor's say they can't cure us but they can treat us, but how do we treat the "what if's" that constantly run through our mind? Living with a chronic illness is stressful, but what if there was a way to avoid all this stress?

When I was first diagnosed with CML I was naive, I believed that all I had to do was eat a magic pill everyday and all my problems would go away. I was new to the CML game and was uninformed; about a month into this journey I started learning the harsh reality of chronic leukemia. In the form of headaches, muscle cramps, nausea and stomach issues the magic pill that was supposed to solve all my problems was beginning to create them. Going out on the weekends wasn't fun anymore. I was told to avoid alcohol because drinking may aggravate my liver. Great, going dry at 25! Further into my research I came across other patients, what were mutations? Nobody ever told me these things exist! What? Blast, that still happens? T315I? People die from CML? This pill was now beginning to seem less and less magical, for $3500/month; naive me, was expecting David Copperfield.

Needless to say the burden of this illness is a lot to bear and could very easily drive a sane person, crazy. Over time though, I have come to certain realizations, all I can do is love my body unconditionally, think enriching thoughts and nourish my soul. By doing these 3 things, having my disease carefully monitored and continuously educating myself as a patient I will have done everything in my power to successfully attack these "terrorist cells".

The human body responds to consistency; regular and challenging work outs, obeying a restful sleep schedule and eating our meals and TKI's at the same time everyday are a few things we can do to put our bodies in a healthy synchronization. Over the last few months I have transformed my diet and have first hand experienced the wonders of Acai berries, turmeric and wheatgrass. I am a firm believer that our diet greatly influences our mental state. In the past I've never been one to express my emotions, but I do now, and it feels great! I also know that my energy is going to flow to wherever I focus my thoughts, I may as well think positively because I have now learned that cancerous cells thrive in acidic environments. With a balanced mind and a body that feels appreciated I am in a better position to serve those around me, which is the last piece of the puzzle, nurturing your soul. There is no greater feeling then giving to those around you, whether its driving a friend home after they've had too much to drink or sharing with others the unique insight on life that CML has given you. When you are living with a chronic illness, uncertainty will always be present. The truth is not everyone responds to their TKI's, not everybody is fortunate enough to be mutation free, more patients then we'd like to believe are intolerant to their pill,. But through simple lifestyle changes every CML'er can be better equipped to deal with the "what if's".

THE PATIENT ADVISORY BOARD

Each pab member, representing one of the canadian provinces or regions, is responsible for facilitating the establishment of regional support groups and disseminating relevant information/education programs, while also defining local issues and bringing them to the attention of the cml society's national advocacy group.

British-Columbia

Shalyn Linklater (Burnaby) has a background in the childbirth field, bringing experience in patient support, education, outreach and advocacy programs to the PAB. Husband Tim was diagnosed in September 2006 with CML, an artist/animator in the film/game industry, currently working as an independent to enable them to enjoy life wherever-whenever. They have 3 active kids who keep busy with running, snowboarding and biking. Email - **bc@cmlsociety.org**

Alberta

Judy Prusky (Calgary) was diagnosed with CML in September 2002, and is a retired junior high school administrative secretary. Judy is married to Gordon, and they have two adult children and two grandchildren. Judy's hobbies include music, swimming, reading and many crafts. Her other pastimes include traveling to the Arctic to see her grandchildren, Lions Clubs International and trying to keep in shape.

Prairies

Margot Miller (Winnipeg) Diagnosed with CML in april 2005, brings expertise drawn from a variety of recreational work over the years. Her involvement has been primarily with seniors in program planning and facilitation in the areas of entertainment, education, physical fitness, palliative care and recreational therapies. Margot also has experience in conflict mediation and advocacy. She received her B.A. In physical education and psychology in 1978 from the university of western Ontario. Margot and her husband Harold have four children. Her interests include yoga, complimentary medicine and nutrition, researching environmental causes of illness and and being an active community member. **Prairies@cmlsociety.org**

Ontario (toronto region)

Stewart Sklar (Toronto) Stewart was diagnosed with CML in march 2003. He is a practicing lawyer in toronto. He has been operating his own practice since 1978 in the preferred areas of real estate, corporate-commercial and wills and estates. A graduate of the university of Toronto (B.A. '73) and the university of western ontario (LL.B. '76), and enjoys woodworking, cooking, fitness and travel. **Toronto@cmlsociety.org**

Québec

Rav is the youngest and newest member of the pab, he will represent quebec and also provide a voice for an often overlooked segment of the CML community-young adults. Young adults face a unqiue set of issues when it comes to living with CML: insurance issues when starting a new job, dating and relationships, living arrangements and how to deal with and explain the disease to peers are just a few. Rav plans to encourage other young CML'ers to join him and have their voices heard, after all the young patients are the ones who should be asking "are these pills gonna keep us alive for the next 50 years?"

Rav is a 27 year old engineer currently living in montreal, he enjoys reading, working out and travelling.

Please note, Rav cannot use his full name as he is concerned about jeopardizing his employement opportunities in the future - sound familiar to any young patients out there?

ASH 2008
Special Report

ASH WAS BLOODY EXCITING

Hello fellow CML patients. If I had to share just one thing with you from the ASH Conference it would be how wonderful it was to meet and hear doctors and researchers from around the world, dedicated to CML research and the care of CML patients. Though CML is an Orphan Disease we garner lots of attention.

Blood is beautiful and a world unto itself. In our CML world things have gone haywire, however most of us are being helped by TKI's. The research shows that the TKI"S are very effective at controlling the majority of CML cases. As patients we are grateful, but we want more. We want a cure. It is a good thing to hope and work towards a cure.

Patients were given a strong voice through Cheryl-Anne Simoneau, President of the CML Society of Canada. Cheryl-Anne was part of an international panel of Doctors and presented the results of the CML Society Patient Survey. She was very well received. Your voices were heard!

"WE ARE THE EXPERTS ON OUR OWN LIVES".

The size and scale of the conference was immense. This Prairie girl was dazzled. The numbers I heard bandied about were 23,000 doctors and researchers in attendance. The conference was jam packed with presentations. It was a terrific networking opportunity. We met many doctors, researchers and drug company representatives, who had a genuine interest in the CML Society and the lives of CML Patients.

On day two we visited a very large hall with booths representing many drug companies. Bristol-Myers Squibb had a very interesting real-time patient centered survey, which we participated in. Many other companies had excellent information packages, and experts who answered our questions. Our CML Patient group talked with ChemGenex researchers who listened and responded to all our questions with utmost sincerity and respect. Novartis Oncology Canada hosted a breakfast for our CML Society members and we covered several areas of interest to CML patients. Gleevec is produced by Norvartis and is the drug that the majority of CML patients are presently being treated with.

The Poster Session that we all attended is like a giant science fair. The Doctors and researchers stood in front of their posters, which outline their latest research. There was a long aisle dedicated to CML related research. It was fascinating to talk to the researchers about invitro CML studies. Vitro today and hopefully translated to successful In Vivo results.

San Francisco is a beautiful, vibrant city. On the trolley ride to Fisherman's Wharf I noticed how many San Franciscans leave their blinds open, and offer quick glimpses into their lives. I saw some beautiful artwork as well as people in various states of undress. It's so much fun hanging on the outside of the trolley, going up and down incredibly steep hills.

Cheryl-Anne, Stewart, Rav and myself felt very energized leaving this International Conference where we had a chance to hear and meet some of the greatest minds in CML research. Speaking of great minds; a shout out to our CML Society Medical advisors Dr.Jeff Lipton and Dr. Pierre Laneuville.

The CML Society of Canada is a respected organization and I was proud to part of the patient delegation to ASH.

Margot Miller
CML Society Prairie Patient Representative

CML SOCIETY
ARTICLE FOR ASH

By Rav

The American Society of Hematology hosted its 50th Annual Meeting and Exposition during the first week of December, because of the fundraising efforts of the CML Society of Canada 4 members of the Patient Advisory Board got to attend the meeting held in downtown San Francisco. This colossal event packed the three main halls of the Moscone Center and was attended by over 23,000 doctors, researchers, patient groups and Pharma professionals from around the world.

The ASH conference is the most popular and widely attended hematology conference internationally, this is where major research accumulated over the past year is presented and major findings are made public. It was at the 2001 ASH where the effects of Gleevec were first presented. Fast forward 7-years: Sprycel, Nilotinib, Bosutinib have been developed, doctors say they can treat 90% of mutations, and encouraging data shows that the dreaded T315I will soon be treatable. What about our quality of life?

ON THE SOAPBOX

The CML Society of Canada was invited to present at the "Overcoming Resistance in CML" panel discussion. The patient representative on the panel was Cheryl-Anne, who presented the results of the Society's "Patients Perspective on their role in the treatment of CML" web survey and focus groups. In brief, the results showed that patients feel the need to be better educated about their disease, and the financial burden of this disease is having a negative impact on the patient's household financials. Interestingly, even though the majority of patients are reporting uncomfortable side effects on their TKI's, only small minorities of doctors are being responsive. British doctor and moderator of the panel Dr. Jane Apperley addressed the audience after the patient results were presented and referred to the findings as "shocking" and "illuminating" (see our website for the full video presentation). Needless to say, the presentation left a strong impression on those in attendance. Cheryl-Anne received invitations to France, Switzerland and England to give her presentation and work with European patient groups.

This was very encouraging news for us, Patients are speaking up and the medical community is being receptive!

When I was your age, we only had Interferon!

When I go to hospital appointments I stick out like a sore thumb, people often think I'm at the blood clinic accompanying a parent or grandparent. Not may people understand the experiences and challenges that come with dealing with a chronic leukemia in your 20's. For this reason I was eager to talk to doctors about their other young patients and requested to be put in touch with them. After meeting with numerous doctors from various countries one thing is clear, increasingly young people are being diagnosed with CML, this isn't just a disease for grandma and grandpa. One American doctor told me that in Korea CML patients are typically getting diagnosed in their 40's compared to the 50+ age group in North America. Doctors do agree that although the results of current treatment are quite good, we need to proactively seek a permanent solution. Patients living longer, increasing number of patients, the younger age of patients and the high cost of drugs all equate to a major strain on our already saturated health care system.

Big Pharma!

All the big names in Pharma came out in full force for the exhibition session. Patients and doctors alike were treated to interactive knowledge tests, our skills were challenged at all the kiosks with games and surveys, from mutation testing to virtual patients to patient/doctor communication survey's it was almost sensory overload. Every booth was equipped with knowledgeable representatives who knew the products inside out and were glad to answer all questions. Many representatives were grateful to meet actual patients, as many of them had never had the chance to see the end users of all their efforts.

What's up Doc?

Having been a CMLer for the past 2 years, I have only seen the patient side of leukemia, i.e. Hospital stays, doctors appointments, blood work, patient groups and websites-so it was quite a unique experience to see the medical sides of our blood disease. At such a busy conference it is difficult to meet all the great doctors and researchers that are working to solve the CML puzzle, but I was fortunate enough to have encountered a handful of doctors that left an impression on me:

The CML Society of Canada is grateful to both Dr. Lipton and Dr.Laneuville for all the time and effort they volunteer towards helping us patients. Both doctors were present at ASH and took time out of their hectic schedules to meet and chat with us. These Canadian docs do a fine job at representing us on an international scale.

ASH – A little bit of this, and a little bit of that

By Cheryl-Anne Simoneau

This year marked the fifth year in a row that I had the pleasure of attending ASH. Thanks to the hardworking dedication to fundraising, I was not alone. Three fellow patient board members and a fellow patient executive committee member of The CML Society of Canada were also able to attend.

Without a doubt, the most exciting thing about this year's ASH was being able to present our findings from our Web Survey and focus groups as part of the panel of the Satellite Symposium funded by ChemGenex and organized by SciMed. Please visit the website to view the 20 minute video presentation. The Panel was composed of some of the leading key opinion leaders for CML. Chaired by Dr. Jane Apperley, the panel members were Dr. Franck Nicolini, Dr. Luke Akyard, Dr. Andreas Hochhaus, and Dr. Cardamas-Quintas.

It was a bit nerve wracking to speak in front of so many people; over 900 participants were in the room. However, the subject matter is very close to my heart. I was very proud to be representing the voice of patients at such an important event.

The CML Education session on Saturday morning was quite interesting. Dr. Michael Deininger headed off the session with a background history on CML. Did you know that it was in 1845 that the first patient diagnosed with CML was in Scotland? A few weeks after another patient was diagnosed in Berlin. Although it was not known at the time, these two patients probably represent the first known case of the disease we come to know as CML. In 1872, it was observed that leukemic stem cells come from the bone marrow. However, it was in a lab in Philadelphia that two researchers working together, Lowell and Hungerford located the Philadelphia Chromosome. This was a very significant event as it showed that cancer, and CML in this case could be traced to a problem in the DNA. Through the decades a variety of treatments have been helping some patients extend their lives, but it was a significant breakthrough by Alexander Levitzki who showed that ABL inhibitors could be effectively used in inhibiting tyrosine kinases and blocking cancer. Today we have three approved Tyrosine Kinase Inhibitors and another one far advanced in clinical trials. However, the cure remains elusive to us.

Dr. Deininger's talk continued on with milestones for monitoring CML patients. A physical exam is carried out at diagnosis when the spleen can be palpitated. Once the patient starts responding to treatment, usually after three months, the physical exam is no longer necessary. CBC's are done every 1 – 2 weeks until a response to treatment is achieved, thereafter at 6-week intervals. Bone marrow biopsies should be done at diagnoses, 6 months, 12 months and 18 months until CCR is achieved, then only afterward if relapse is suspected. Quantitative PCR every 3 months once CCR has been achieved, and FISH in Uncertain diagnosis (typical clinical presentation, but metaphase cytogenetics not successful or Philadelphia-chromosome negative). Every 3 months if no access to high quality quantitative PCR monitoring. Mutation testing should be done when there is suspected progression or resistance. ***Editor's note:*** *These guidelines are different from the Canadian CML Guidelines which are currently being updated. Our Medical Advisors will be providing us with the new guidelines as soon as they are available, please check our website for the latestversion.*

Dr. Junia Melo provided a good overview of the TKI's on the market today. Dr. Melo mentioned that resistance to Imatinib is becoming a significant problem even though Imatinib still achieves remarkable clinical results. There are many factors, such as genomic instability, and the fact that since the residual disease is never eliminated because Imatinib does not affect the primitive stem cell progenitors. The results that were presented shows that all of these second generation drugs provide significant clinical results. Dr. Melo also provided good coverage of a variety of other types of drugs not specifically ABL Kinase inhibitors that are being studied to combat serious mutations such as T315I. In the end, she reminded us that it is very likely that mutations causing resistance to the second-generation drugs will likely arise and that it is probably not feasible to think that monotherapy alone will be sufficient for the entire population of patients. The trick just may be combination therapies with ABL Kinase Inhibitors and non ABL Kinase Inhibitors.

The final talk was by Dr. Catriona Jamieson and it was on the CML Stem Cell population. The Hematopoietic Stem Cell population was identified over thirty years ago, but it is only recently that work has progressed in this area. Recently, work is focusing on the quiescent stem cells, which are rarely ever affected by the currently marketing TKI's. Moreover Dr. Catrionia stated that in fact Quiescent cells with mutations prior to treatment therapy seem to somehow become more robust and resistant to Imatinib therapy (the current front line therapy). This would indicate that eradicating these stem cells is highly unlikely with a monotherapy. The good news is that science is moving closer to understanding how some of these pathways can be disrupted and what it might take to eradicate these stem cells. Better still, several new drugs in development that are aimed at some of the molecular mechanism. Some of the names used such as "sonic hedgehog" made us stop and think about who names these things.

For complete abstracts on these talks, please visit our website www.cmlsociety.org and click on the link to the ASH educational session.

Overall,this was a very good session and we were all feeling quite enthusiastic afterwards.

The next exciting session to report on was the IRIS seven-year data, and happily, there are no new surprises concerning adverse events or additional types of side effects.

We also liked the sessions on combining Interferon with Gleevec. The idea that we can combine drugs is a significant strategy and research must continue in this area. Particularly the study presented by Dr. Francois Guilhot: Randomized Comparison of Imatinib Versus Imatinib Combination Therapies in Newly Diagnosed Chronic Myeloid Leukaemia (CML) Patients in Chronic Phase (CP): First Results of the Phase III (SPIRIT) Trial from the French CML Group (FI LMC)

This study randomized patients into several arms: 400 mg of IM, 600 mg of IM or 400 mg of IM with Ara C, and finally 400 mg of IM with Pegylated Interferon. The patients with the highest percentage of reaching MMR, was in the pegylated IFN and IM combined group. This was quite exciting news and given the earlier discussions on the real need to combine therapies to improve outcomes for patients, we look forward to future follow up from this trial.

We were all quite happy to be heading home after four intense days of listening to talks and staying up late. We did take some time to ride the cable cars and sample some of the local cuisine. It is so much fun making this trip with such good friends and fellow patients. We also met up with other patients from the International CML community, such as Jan Geissler from Germany, Giora Sharf from Israel.

Strategies
aimed at eliminating primitive chronic myeloid leukemia stem cells.

We warmly welcome Dr. Luke Peterson and thank him very kindly for his contribution to our newsletter. Dr. Peterson presented his research at ASH this year and Margot Miller, our Patient Representative from Winnipeg, Manitoba met with him during the poster sessions.

Chronic myeloid leukemia (CML) is associated with the presence of a chromosomal aberration identified in 1960's known as the Philadelphia chromosome. This chromosomal alteration fuses portions of human chromosome 9 to chromosome 22 and leads to the inappropriate partial fusion of two genes which form a gene called BCR-ABL. The BCR-ABL gene encodes an enzyme, known as a tyrosine kinase, with aberrant signaling activity which promotes the growth and survival of specific white blood cells or leukocytes leading to the onset of CML. This malignancy is characterized by the continued uncontrolled accumulation of mature white blood cells. The most effective therapy for CML centers on the use of specific tyrosine kinase inhibitors that block the function of BCR-ABL, leading to the collapse of its kinase and aberrant signaling activity. Suppression of BCR-ABL kinase activity results in the death of most CML cells and drugs like Imatinib and others provide very effective therapy, but not cure, for CML. The development of Imatinib for the treatment of CML has become the ultimate example of targeted therapy, since it specifically effects only the protein that promotes this malignancy (BCR-ABL) and is non–toxic to uninvolved cells or tissues. Indeed, the search for other "tumor-specific" targets and selective inhibitors of those targets in other tumors has been stimulated by Imatinib's success in CML and is a main thrust in cancer biology and drug development.

Since approval of Imatinib for first-line therapy for CML patients in 2002, a great deal of clinical data has shown its remarkable efficiency. However, various observations have demonstrated that next to some limited toxicity issues that might arise, there are also some drawbacks and limitations. This was first described in patients where Imatinib's anti-CML activity was diminished and correlated with the appearance of mutations within the BCR-ABL gene itself, which altered the BCR-ABL protein structure blocking the effective binding of the drug to its mutated target. Multiple mutations have been described in a percentage of patients that leads to the loss of Imatinib's ability to inhibit BCR-ABL activity and suppress the growth and expansion of CML. In addition, it has become apparent that Imatinib efficiently eliminates more mature blood cells that accumulate in CML patients, while not affecting the more primitive malignant blood lineage known as the leukemia stem cells. These cells have the ability to survive even in the presence of high concentrations of of the drug through a mechanism that is not understood but may be related to the specific biology of stem cells and not highly associated with the presence of mutations within BCR-ABL. Therefore, the emerging objective in CML research is to understand the mechanism of CML stem cell survival in the presence or absence of Imatinib.

At the University of Michigan, under the guidance of CML clinical and translational researcher, Dr. Moshe Talpaz, various strategies are aimed at understanding this issue both in the clinic and at the laboratory bench. These studies are also aimed at defining new strategies and testing or developing new drugs or agents that extend treatment options and have the capacity to eliminate or cripple the CML stem cells. The first strategy recognized as a viable treatment option was to reintroduce the previously successful interferon-alpha treatment for CML. During the in the 1980's CML patients that were not eligible for bone marrow transplantation were treated with interferon-alpha with limited success but also longstanding benefit in some (7-10%), where no additional or continual therapy was needed. However, due to the toxicity of this regime and limited success when compared to rapid clinical activity and limited toxicity of Imatinib, the use of interferon diminished. None the less, the longstanding success in eliminating CML in a subset of patients suggests that interferon affects CML stem cells and prevents disease re-emergence. Therefore, our team has initiated a Phase II study of interferon-alpha sequentially combined with Imatinib for the treatment of CML patients, where the primitive blood lineage will be isolated from patients to monitor the presence of CML stem cells after treatment. This approach is aimed to provide rapid control of CML by Imatinib and the potential curative advantage of interferon-alpha.

Other strategies are also being pursued that will complement the clinical activity of Imatinib and have potential to effect the CML stem cell as well. Some new compounds that affect other specific targets in CML are demonstrating that this strategy may be fruitful. One protein that is known to suppress tumor formation but is commonly mutated in many cancers is TP53 or p53. The inactivating mutations of p53 are devastating in that the beneficial control of aberrant cellular growth and survival are lost. Fortunately, in CML p53 mutations are very uncommon, being only present in a small percentage of patients in the most advanced stage of disease. Therefore our laboratory is attempting to manipulate this protein to tackle and cripple the CML stem cells. At the University of Michigan, Dr Shaomeng Wang has designed and developed a small molecule that leads to a temporary increase in p53 protein levels which triggers growth inhibition and killing of cancer cells. Our team has a collaborative study with Dr. Wang which was presented at the 50th American Society of Hematology (ASH) in San Francisco. Our findings are that the combined use of Dr. Wang drug with Imatinib enhanced the killing of leukemia stem cells from CML patients in the laboratory. We are now preparing to advance our studies into animal models that will enhance our knowledge on the safety and efficiency of this combined treatment regime.

Other agents and compounds are also under investigation for the treatment of leukemia and leukemic stem cells. Dr. Nicholas Donato and his colleagues at M.D. Anderson and now here at the University of Michigan are examining the pre-clinical activity and development of a novel signaling molecule inhibitor. His investigation has lead to the discovery of a series of compounds called degrasyns that promote cell death in various leukemia and solid tumor cells through a very unique mechanism involving the displacement of specific tyrosine kinases from their "normal" environment into a cellular compartment where they are unable to signal or communicate within their protein network. More recently a new derivative within this series was tested in our laboratory for its activity against CML stem cells, which we also reported at ASH. We observed direct elimination of leukemia stem cells that was enhanced by combining this agent with Imatinib. This new agent is in very early stages of development and is being further tested on other leukemia primary specimens to assess its potential use in various blood malignancies.

Our laboratory and clinical team at the University of Michigan is focused on more effective treatment options for CML and other blood malignancies. Our aim is to develop agents and regimes that efficiently control and/or eliminate leukemia stem cells with the ultimate goal of finding a "cure" for this disease.

Biosketch of
Dr. Luke F. Peterson

Born on the island Aruba, Dr. Peterson embarked to pursue his studies in the Netherlands where he attained his Bachelor degree in Biochemistry and a Masters degree in Biology at Utrecht University. He then worked at Utrecht University Academic Hospital in Dr. C. Lipps laboratory investigating mutations in the RET gene and cancer genetics of Multiple Endocrine Neoplasia type 1 and 2. Subsequently, he moved to Manchester in the UK to enroll in the PhD program at the University of Manchester and worked under the guidance of Dr. J.D. Norton at the Paterson Institute for Cancer Research, Christie Hospital, studying genes involved in the B cell malignancy Multiple Myeloma. During preparations of his thesis, he was offered an opportunity to go to San Diego, California in the US by Dr. D.E. Zhang to work on studies involving the biology of myeloid leukemia specifically associated with the chromosomal aberration involving chromosomes 8 and 21, which leads to the production of a fusion gene called AML1-ETO. During his time in San Diego he graduated from the PhD program in Oncology from the University of Manchester in 2002. In his period in San Diego at the Scripps Research Institute in Dr. D.E. Zhang's lab he was involved in identifying a shortened aberrant version of the AML1-ETO fusion gene that aggressively promotes the induction of acute myeloid leukemia in mice, and identification of gene(s) that cooperate with AML1-ETO in leukemia development. In addition, he was involved in studies pertaining to the mechanisms of function and control of the native gene AML1 next to AML1-ETO and the AML1-ETO9a genes. In the summer of 2007 he relocated to the University of Michigan were he is pursuing avenues in basic cancer biology and translational research dedicated at finding solutions for eradicating or crippling leukemia stem cells in CML and other hematological malignancies.

Dear Fellow CML Patient:

This chart contains a comprehensive list of all known drugs and food that have the potential to interact with Tyrosine Kinase Inhibitors such as Gleevec®, Sprycel® and Tasigna®. It is always very important to make sure your doctor knows what other drugs you may be taking other than your primary drug to treat your CML. Inadvertently combining TKI's with any of the food or drugs on this list may have some consequences such as preventing you responding to drug therapy and/or experiencing additional side effects. Please bring this chart with you on your next doctor's visit and review the list with your doctor if you have any concerns.

1 POTENTIAL TO PROLONG THE QT INTERVAL

Anti-arrhythmic drugs	Other drugs
Amiodarone	Chloroquine
Disopyramide	Halofantrine
Procainamide	Clarithromycin
Quinidine	Haloperidol
Sotalol	Methadone
	Anthracycline *(at cumulative high-dose)*

2 POTENTIAL TO INCREASE PLASMA CONCENTRATIONS*

CYP-3A4 inhibitors ▲	Antibiotics *(Fluoroquinolones)*	Antineoplastics
Antifungals	ciprofloxacin	Vinblastine
Ketoconazole	norfloxacin	Vincristine
Itraconazole	Antivirals	Vinorelbine
Fluconazole	Atazanavir	Doxorubicin
Voriconazole	Indinavir,	Others
Terbinafine	Nefazodone	Isoniazid
Antibiotics *(macrolides)*	Nelfinavir	Diltiazem
Erythromycin	Ritonavir,	Mifepristone
Clarithromycin	Saquinavir	Cimetidine
Troleandomycin	Delavirdine	Ranitidine
Telithromycin	Antidepressants	Quinidine
	Fluvoxamine	Amiodarone
	Nefazodone	
	Norfluoxetine)	

3 POTENTIAL TO DECREASE PLASMA CONCENTRATIONS*

CYP-3A4 inducers ▼	Antivirals	Barbiturates
Glucocorticoids	Efavirenz	Phenobarbital
Dexamethasone	Nevirapine	Oral Hypoglycemics
Antibiotics	Etravirine	Pioglitazone
Rifampin	Anticonvulsants	Troglitazone
Rifabutin	Carbamazepine	
	Phenytoin	

4 DRUGS WHOSE PLASMA CONCENTRATIONS MAY BE AFFECTED (INCREASE) ▲

Benzodiazepines	Calcium Channel Blockers	Antineoplastics
Alprazolam	Amlodipine	Taxol
Diazepam	Diltiazem	Vincristine
Midazolam	Felodipine	Irinotecan
Triazolam	Nifedipine	**Others**
Immunomodulators	Verapamil	Tamoxifen
Cyclosporine	**HMG-COA Reductase Inhibitors**	Warfarin
Tacrolimus	Atorvastatin	Sildenafil
Sirolimus	Lovastatin	Methadone
Prokinetic	Simvastatin	Clopidogrel
Cisapride	**Oral Contraceptives**	Dextromethorphan
Antihistamines	**Analgesics**	Trazodone
Chlorpheniramine	Acetaminophen	Quetiapine
	Codeine	

5 DRUGS WHOSE PLASMA CONCENTRATIONS MAY BE AFFECTED (DECREASE)▼

Levothyroxine

6 VACCINES [1,2]

Flu vaccine or any other *(Interferon-inducer)*
During the immediate period following vaccines administration:

1. Patient antibody response to a vaccine may be decreased.

2. Immunization of patients on Gleevec should be done with extreme caution and not with live virus vaccine.

7 HERBAL PRODUCTS INTERACTIONS

(Decrease)▼	(Increase)▲	(Increase)▲
St. Johns Wort	Kava-kava *(Piper methysticum)*	Black cohosh *(cimicifuga racemosa)*
	Goldenseal *(Hydrastis canadensis)*	Milk Thistle *(Silymarin)*
	Cat's claw *(Uncaria tomentosa)*	Valerian root *(Valeriana officinalis)*

8 HERBAL PRODUCTS NOT LIKELY TO INTERACT

Gingko *(Gingko biloba)*	Teas *(dandelion, peppermint, chamomile)*	Glucosamine chondroitin
Garlic *(Allium sativum L.)*	Green Tea *(camellia sinensis)*	Genistein *(isoflavinoid)*
Saw palmetto *(Serenoa repens)*	Ginseng *(Panax spp)*	
Siberian ginseng *(Eleutheroccus senticosus)*	Dong quai *(Angelica sinensis)*	

9 FOOD/BEVERAGE INTERACTIONS (INCREASE)▲

Gingko *(Gingko biloba)*	Teas *(dandelion, peppermint, chamomile)*	Glucosamine chondroitin
Garlic *(Allium sativum L.)*	Green Tea *(camellia sinensis)*	Genistein *(isoflavinoid)*
Saw palmetto *(Serenoa repens)*	Ginseng *(Panax spp)*	
Siberian ginseng *(Eleutheroccus senticosus)*	Dong quai *(Angelica sinensis)*	

10 FOOD/BEVERAGE TO AVOID IN CASE OF GASTROINTESTINAL (GI) SIDE EFFECTS DUE TO GLEEVEC

Spicy foods	Caffeine	Dairy products
Chocolate	Citrus juice	

This chart has been compiled with the collaboration of the medical departments at both Bristol Myers Squibb and Novartis Oncology.

It was reviewed by our Medical Advisors and Patient Advisory Board Members, and will be updated on a regular basis.

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THE UNCONSCIOUS WOUND AND ART THERAPY/ JOURNALING

In 2002, I was diagnosed with CML. When I told my sister-in-law, Suzanne, who is an artist and studied art therapy, about this, she suggested that I might want to study basic art as a way of getting to know myself and work on my mind/body connection. This might help me discover my 'unconscious wound' to start my healing process. She suggested learning how to create Mandalas as a form of art journaling.

A Mandala is a Sanskrit word-meaning center, circumference, or magic circle. Carl Jung associated the Mandala with the Self, the center of the total personality.

Thus, the journey to my unconscious wound began. With a guided meditation to get in touch with the feelings in my body, mind and soul, I began my Mandala. I would draw a circle using a dinner plate on paper, get my colouring pencils, and start expressing myself through the different colours and forms I used. Once that was completed, I would concentrate while staring at it, listening for what came up through my emotions. My main objectives were to see what it was in what shapes and colors I had used to create it with that would help me learn more about myself. I would immediately write down what came up … simply jotting down one or two words as they came to me. In the struggle between personal life and work life we resort to all sorts of ways to try to cope in this ever-changing world. The outside world becomes so "noisy" that we loose touch with ourselves. This is essentially how the unconscious wound is created. Art therapy gives you the time to create a quiet space in your hectic schedule to check in with yourself. Sometimes, the unconscious wound was so painful that I couldn't go any further in trying to find out what it was.

Some of the feelings and thoughts that came up helped me to explore and connect with some of the deeper essences of myself. I felt a lot of unexpressed creativity, which came up as anger. I had lost my ability to set my own boundaries.

As I continued my art journey, I began to feel better and became aware of my inner strength. I slowly got into remission (of course, Sprycel helped).

Doing these simple Mandalas at home on a daily basis as one would write in their diaries is a very powerful tool. I had the sudden urge to express myself at another level in art. I started art classes. The theme was always a flower or as I call it a 'healing flower' with the intention to cause peace, love and health in the World. My first flower is entitled 'Unconscious Healing'.

I continue doing the Mandalas and am discovering more and more of the unconscious wound, which is slowly healing in my soul, mind, heart and body.

Rita Levig

Feedback and Subscription Form

Please give us your comments and ideas for future articles, as well as your feedback on the articles in the current issue.
By e-mail: subscription@cmlsociety.org **By regular mail:** CML Society, 103 Sussex Unit 13, Beaconsfield, Quebec, H9W 6C7

☐ I would like to subscribe to the newsletter and receive information by E-mail regarding emerging issues, as well as national and regional events organized by the CML Society of Canada.

☐ by e-mail at _____ (e-mail) ☐ by regular mail at _____

_____ (complete postal address)

Name: _____ Region or city: _____

Becoming an Active Member:

☐ I would also like to become actively involved in the CML Society, and would like to know more about the opportunities.

Please contact me by phone at _____ or by e mail at _____

NOTE: Your name and private information remains strictly confidential and highly protected by the CML Society and will not be circulated under any circumstances.

The CML Society of Canada

The Patient Advisory Board (PAB) Update

We wish to warmly welcome as the newest, and youngest member of our patient Advisory Board. Rav represents a growing population of people under thirty afflicted with this disease and will offer lots of insights on how to cope with such a serious diagnosis at such a young age.

Mission Statement:

The CML Society unifies and brings the voice of survivors to the management of Chronic Myelogenous Leukemia (CML), the elimination of suffering, and the improvement of care and quality of life issues - through patient support and networking, education, advocacy, and encouraging research.

The Board of Directors of the CML Society of Canada

Cheryl-Anne Simoneau,
President

Stewart Sklar, LL.B.,
Secretary

John Sao Miguel
Treasurer

Check the website for updates

Medical Advisor
Dr. Pierre Laneuville,

is an Associate Professor (GFT-U) in the Department of Medicine and Oncology at McGill University and the former Head of Hematology for the McGill University Health Center. Dr. Laneuville is best known for his research on the molecular mechanisms underlying the genesis and transformation of chronic myelogenous leukemia. He is the current President of the Canadian Hematological Society and Chairman of the Canadian Consensus Group on the Management of Chronic Myeloid Leukemia (CCGM-CML).

He has served on numerous basic and clinical research panels including the Medical Research Council of Canada, the Leukemia Research Fund of Canada, the National Cancer Institute of Canada Clinical Trials Hematology Executive, and the Canadian Blood and Marrow Transplant Group. He has held a number of research grants supported by the MRC, LRFC, CRSI, MSSC, and is actively engaged in clinical trials for hematological malignancies and stem cell transplantation.

Medical Advisor
Dr. Lynn Savoie ,

is a Clinical Assistant Professor in the Departments of Medicine and Oncology at the University of Calgary as well as a member of the Department of Hematologic Malignancies and Bone Marrow Transplantation at the Tom Baker Cancer Centre in Calgary. Her interests lie in myeloid malignancies and medical education. She is a member of the Canadian Hematology Society, the Canadian Blood and Marrow Transplant Group as well as of the National Cancer Institute of Canada. She is a local primary investigator for a number of clinical trials including in CML. She has helped update the Canadian CML treatment Consensus Guidelines. She is also actively involved in Physician evaluation as an examiner for the Royal College of Physicians and Surgeons of Canada in Internal Medicine and Hematology.

Medical Advisor
Dr Robert Delage

is an Associate Professor in the Department of Medicine at l'Université Laval and Head of le Centre Universitaire d'Hématologie et d'Oncologie de Québec, at the Centre Hospitalier affilié, Hôpital de l'Enfant-Jésus in Québec city. Dr. Delage is also the director of the molecular biology laboratory of his institution and developed an expertise in the laboratory evaluation of CML diagnosis and response. He has a particular interest in hematopoietic stem cell transplantation and CML and is involved in numerous national and international clinical trials. He served as a member of the examination board in haematology at the Royal College of Physicians and Surgeons of Canada and was Chair of the committee between 2005 and 2008.