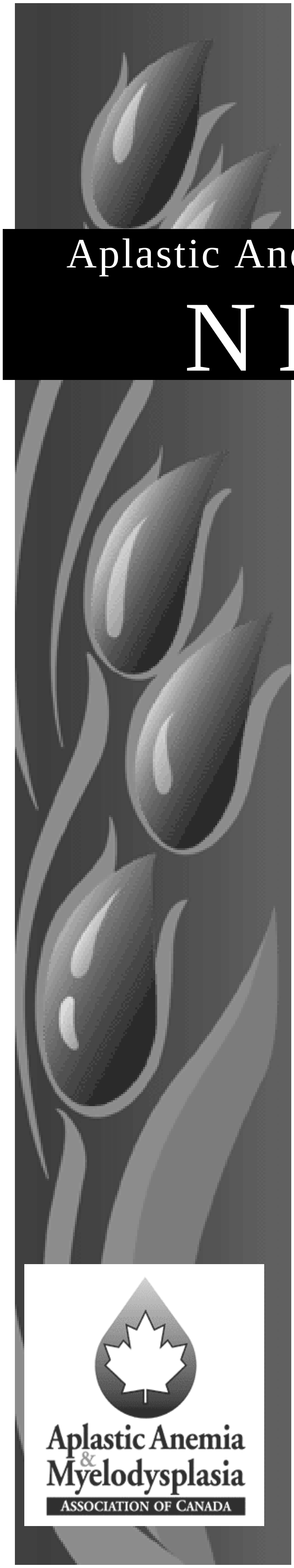
Education
Support
Research

Winter 2016



Aplastic Anemia & Myelodysplasia Association of Canada

NEWSLETTER

Message from the Chair

I love this time of year. The leaves have changed colour and begun to fall, the air is cool and crisp, and cozy evenings at home are spent with family. It's also the end of a very busy time for all of us at AAMAC.

On October 15, AAMAC held the annual patient education day in Moncton, New Brunswick. We were so pleased with how many people took time out of their busy weekends to join us at the Delta Hotel Beausejour.

We are so very grateful for the wonderful slate of medical professionals who shared their knowledge with all in attendance. Many thanks to Celgene, Novartis and Alexion for sponsoring education day and making this annual event possible and also all of the amazing AAMAC volunteers who give of their time to help us with coordination and at the event itself. Education Day was recorded and will be available online in the coming weeks for those who weren't able to attend.

The annual Education Day also coincides with AAMAC's Annual General Meeting and meeting of the Board. I would like to take this opportunity to thank Steven Parks who recently stepped down from the Board. We have two new Board members joining us this year: Haydn Liang and Sanjeev Parmar. Both Haydn and Sanjeev bring a wealth of knowledge to AAMAC and we look forward to their contributions in the year to come. I am also deeply honoured to have been nominated to the position of Chair. I look forward to working with the Board and staff to continue to ensure AAMAC serves our patients and their families.

Plans are well underway for regional support meetings across Canada in 2017, please keep an eye on the AAMAC website for information on events near you.

In addition we are able to confirm that Education Day 2017 will be held in the Vancouver area in September 2017. We will keep you posted with details as they become available.

Sincerely and best wishes for the holiday season,

Ashley Oakes
Chair of the Board
AAMAC

The Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) provides information about aplastic anemia (AA), myelodysplasia (also called myelodysplastic syndrome or MDS) and paroxysmal nocturnal hemoglobinuria (PNH) to the public; operates a nationwide support network for patients, families and medical professionals; supports Canadian Blood Services blood programs and OneMatch Stem Cell and Marrow Network; and raises funds for medical research.

The Aplastic Anemia & Myelodysplasia Association of Canada Newsletter is published 4 times a year. The contents are not intended to provide medical advice, which should be obtained from a qualified health professional. No part of this publication may be used or reprinted without written permission. For submissions, inquiries or comments, please contact us at:

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BC Update

By Janice Cook

Hello all, it's already time for my yearly reminder to ask your doctor if you should get a flu shot. Apparently flu season has started early in some areas, but the good news is that the flu vaccine is a good match to the virus this year. And remember as we head into cough and cold season that your best defense other than avoidance, is hand washing with soap and water and avoiding people with colds.

In late August, a number of pediatric and adolescent patients and their families enjoyed a special education and support meeting at Vancouver Children's Hospital. This meeting and speakers were arranged by Dr. Kirk Schultz, who has a long history with AAMAC and is a member of our Medical and Scientific Advisory Committee.

Last month, in Kamloops, a small group of strangers met for lunch, and 90 minutes later, new friends left with assurances that they would meet each other again. Patients and their spouses have different experiences with bone marrow failure disease, different levels of understanding, and different treatment programs, from watch and wait to supportive care to transplant. But I think we all learned from each other and enjoyed meeting fellow community members who live with some of the same issues. Family, friends, or neighbours, it really doesn't matter who you can talk to, as long as you have someone when you need it.

Making connections is one of the best things about a small support group meeting, and why we encourage people to come out even if there is no speaker.

For up to date information on our three bone marrow failure diseases and treatment, excellent local speakers, a great lunch, and chance to meet more people who live with the same illness, one of the best places is an AAMAC annual Education Day. We have started the planning for September 30, 2017 in Vancouver and we hope to see you there.

Take care everyone.

Atlantic Region Update

By Gwen Barry

AAMAC's Atlantic Region had a busy Autumn. The Halifax Support Group gathered in early October at the home of Jackie MacDonald for lunch and planning for upcoming events.

On October 15, Atlantic Region hosted a Patient Education Day in Moncton, New Brunswick. From Atlantic Canada, those who registered included patients and caregivers from New Brunswick and Nova Scotia, as well as registered nurses from New Brunswick. The nurses had a breakout session at lunch time, in order to participate in an MDS training module designed by AAMAC especially for nurses.

A panel discussion was held, with Mark Brennan of New Brunswick, Linda O'Brien of Nova Scotia, and Ashley Oakes of British Columbia sharing their unique journeys with AA/MDS/PNH, followed by a question and answer period.

Also included were some very informative presentations by hematologists from New Brunswick, Nova Scotia, and Montreal, as well as a Psychologist's presentation on 'How to Live with Chronic Medical Conditions,' and the associated stress.

Atlantic Region of AAMAC has come full circle now, having hosted a Patient Education Day in each of Nova Scotia, Newfoundland and New Brunswick in the past four years. And there will be more in the coming years.

The Annual General meeting was held at the end of Education Day, with two volunteers from Atlantic Canada voted onto AAMAC's Board of Directors for 2016-17, namely Jennifer

Garvey and me.

The Halifax Support Group is holding a Christmas Pot Luck Luncheon in Halifax, on Saturday, November 26 at the home of Dolores d'Entremont. It is for AA/MDS/PNH patients and their families. Anyone living in Halifax and the larger surrounding area is welcome to attend. For further information, please contact Dolores d'Entremont at dodnt10@gmail.com or call (902) 477-0958.

If you have AA, MDS, or PNH and would like further information on AAMAC's activities in Atlantic Region, and on the kinds of support that are available, please contact me as AAMAC's Atlantic Region Coordinator at gwenb@eastlink.ca or (902) 864-8872.

Dr. Sharif presents on the topic of Iron Overload at AAMAC's annual Patient Education Day.

Ontario Chapter Update

By Darlene Edmonds, Regional Support Liaison, Ontario

Well it's been a very busy fall. I'd like to thank all of the participants who joined us in Toronto on Saturday, September 17, 2016 at 300 Bloor Street United Church. Cindy Murray was our guest speaker on the topic of Managing Common Side Effects of MDS Treatments. Cindy's presentation was very interesting and interactive, with many questions and answers. A special thank you to Cindy Murray for her contribution of time and her knowledge of this topic, which she shared with us.

In October, we visited London, Ontario, on Saturday, October 29, 2016 from 10 a.m. to noon. A total of 17 members gathered with Dr. Cyrus Hsia at Wellspring Cancer Support Centre. Dr. Hsia spoke on Iron and Iron Overload. Dr. Hsia has a way of explaining and engaging everyone in the discussion, as well as adding a bit of humour into his presentation.

As you know November is Caregiver Month. We were thrilled to be able to offer a Patient Support Group meeting. On Saturday, November 5, 2016 in Hamilton, we welcomed Corinna McCracken and Maggie Jamieson, two social workers from Hamilton Health Sciences who presented on the topic of Caregivers: Quarterback, Cheerleader and Caring for Self! This was a very interactive session.

Over the next few months we'll be planning the spring 2017 Patient Support group meetings for London, Hamilton, Toronto, and Kitchener, with possible expansion into Chatham, Oshawa and the Cobourg region. For any patient support group meeting please call or email the office to register or email info@aamac.ca or 1 (888) 840-0039.

These patient support group meetings provide a safe environment for patients, caregivers and health care providers to come together to learn and share. We can all learn from one another.

Special thank you to Celegene, Novartis and Alexion for their continued support for the patient support group meetings.

If you have a topic or a suggestion for a meeting, or if you've heard someone present whom you were really impressed with, please share the details with the AAMAC office.

During the Fall, AAMAC volunteer Caroline Laughlin and I have been setting up the AAMAC resource table at the Sunnybrook Cancer Clinic one or two Mondays per month. If you happen to be there when we are, please drop by and say hi.

I would also like to extend a special thank you to Caroline for her assistance at the clinic days.

I look forward to meeting you at one of the upcoming patient support meetings this coming Spring. Please continue to watch the website for future webinars and patient support group meetings for 2017.

TEAM Award

Established by Celgene Corporation in 2009, **T**he **E**xcellence in **A**dvocacy **M**edal's purpose is to recognize an individual or group that has contributed significantly to advocacy efforts, improved care, treatment options or improved access to care and treatment options on behalf of bone marrow failure patients.

The award is a plaque given by Celgene at an AAMAC event. The award includes a $5,000 donation to AAMAC.

In October, Dr. Stephen Couban became the recipient of the 2016 TEAM Award.

Dr. Stephen Couban has been a champion of his patients in the Maritime Provinces for many years. About 20 years ago, he was instrumental in starting an Annual Stem Cell Transplant Survivor's Banquet for as many as 300+ patients and their families from all over the Maritime Provinces. This event is still going strong. Patients gladly attend from the far reaches of the Maritimes. And those who received bone marrow and stem cell transplants decades ago, are amazed that he still remembers their names to this day. It is evident from the annual banquet ritual of patient testimonials, where they dare to tease this distinguished gentleman, that he is highly regarded by patients and caregivers alike.

Further, Dr. Couban has been a member of AAMAC's Medical and Scientific Advisory Committee for a number of years, and has always been willing to provide advice to AAMAC at both the national and regional levels. And despite his busy schedule, such advice is always provided in a speedy manner.

Congratulations Dr. Couban!

Dr. Stephen Couban (centre) receives the TEAM Award for being a long-time champion of patients in the Maritimes. Pictured with him are Sylvain Clermont, Celgene's Senior Manager, Government and External Affairs (left) and AAMAC Chair Ashley Oakes (right).

Delivery of cord blood stem cells important milestone

This news release was issued by Canadian Blood Services on September 7, 2016.

Canadian Blood Services' Cord Blood Bank has delivered a cord blood unit for the transplant of stem cells to the first Canadian patient.

"We're so excited to be giving a Canadian patient the gift of life," says Dr. Heidi Elmoazzen, Canadian Blood Services' director, cord blood bank and stem cell manufacturing. "We expect this will be the first of many lifesaving transplants from our bank for Canadians yet to come."

Rich in stem cells, cord blood is collected from the umbilical cord and placenta of volunteer donors shortly after birth. They can, in turn, be transplanted if an appropriate donor and recipient match is found. Cord blood stem cells are used for treating over 80 diseases and disorders such as leukemia, lymphoma, aplastic anemia, inherited immune system and metabolic disorders, as well as sickle cell anemia.

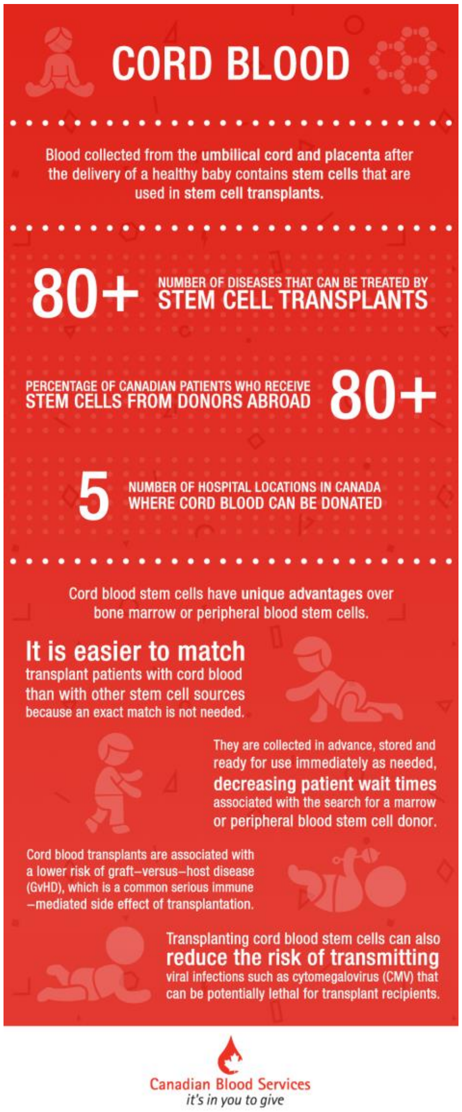
As of today, Canadian Blood Services has collected over 11,200 cord blood units from mothers across Canada and has banked over 1,400 units which are available for searching and matching. As the cord blood bank increases its inventory, due to the generosity of mothers donating their baby's cord blood, the number of cord blood units available for successful matching and transplantation will continue to grow.

At any given time, Canadian Blood Services' OneMatch Stem Cell and Marrow Network is searching on behalf of hundreds of Canadian patients in need of an unrelated blood stem cell donor. Approximately 75 per cent of patients who need a blood stem cell transplant are unable to find a suitable match within their own family.

"Many Canadian patients have unique stem cell matching needs reflective of Canada's extensive ethnic diversity," says Dr. Elmoazzen. "The goal of Canadian Blood Services' Cord Blood Bank is to create more transplant opportunities for Canadian patients with a cord blood bank that is reflective of the unique diversity that we see here in Canada."

Canadian Blood Services' Cord Blood Bank is part of an international network of publicly banked cord blood units. Currently there are almost 700,000 publicly banked cord blood units around the world. However, even with this access, it is still not possible to find a match for about half of the patients in this country who need a stem cell transplant. Canada needs to continue to build the most ethnically diverse public cord blood bank possible to provide Canadian patients with more opportunities to receive a stem cell transplant.

"The delivery and ultimate transplantation of the first cord blood unit to a Canadian patient represents an important milestone," says Dr. Graham Sher, chief executive officer with Canadian Blood Services. "It is the realization of a commitment, several years in the making, to provide a public cord blood bank that creates transplant opportunities *For All Canadians*, the theme of our recent fundraising campaign."



CORD BLOOD

Blood collected from the **umbilical cord and placenta** after the **delivery of a healthy baby** contains **stem cells** that are used in **stem cell transplants.**

80+ NUMBER OF DISEASES THAT CAN BE TREATED BY STEM CELL TRANSPLANTS

PERCENTAGE OF CANADIAN PATIENTS WHO RECEIVE STEM CELLS FROM DONORS ABROAD 80+

5 NUMBER OF HOSPITAL LOCATIONS IN CANADA WHERE CORD BLOOD CAN BE DONATED

Cord blood stem cells have **unique advantages** over bone marrow or peripheral blood stem cells.

It is easier to match transplant patients with cord blood than with other stem cell sources because an exact match is not needed.

They are collected in advance, stored and ready for use immediately as needed, **decreasing patient wait times** associated with the search for a marrow or peripheral blood stem cell donor.

Cord blood transplants are associated with a lower risk of graft–versus–host disease (GvHD), which is a common serious immune –mediated side effect of transplantation.

Transplanting cord blood stem cells can also **reduce the risk of transmitting** viral infections such as cytomegalovirus (CMV) that can be potentially lethal for transplant recipients.

Canadian Blood Services
it's in you to give

New Guidelines Mean More Donors Needed

This Canadian Blood Services news release was issued on October 24, 2016. Part of AAMAC's mandate is to encourage eligible Canadians to give blood. We encourage you to help promote the blood donations that many of our members rely on.

100,000 new donors needed across the country this year alone

Canadian Blood Services is changing its guidelines for iron levels to further promote health and wellness among blood donors. Female donors will need to wait longer between blood donations and male donors will need to pass a slightly stricter hemoglobin test.

Starting December 10, female donors will need to wait 12 weeks between blood donations, replacing the current eight week waiting period. The minimum allowable hemoglobin level for male donors will increase starting March 5, 2017 from 125 g/L to 130 g/L.

"We continue to promote the health and wellness of donors as they donate the important and generous gift of life," says Mark Donnison, vice-president of donor relations, Canadian Blood Services. "Many donors will not be able to donate as often, so others must step forward to fill this gap by giving blood and encouraging friends and family to make giving a part of their lives."

Patients are relying on 100,000 new donors from across the country to give blood this year alone. More new donors are needed right now to help save lives. Canadian Blood Services is also calling on eligible donors to book an appointment today while walk-ins are also welcome at all clinics.

To book an appointment, use the Give Blood App or visit blood.ca. Those with appointments are encouraged to keep their appointment and bring a friend or family member to donate with them.

Quick Facts

- Less than 400,000 Canadians actively donate blood.
- One in two Canadians is eligible to donate but only one in 60 give.
- Hemoglobin is a protein found in red blood cells which is necessary for carrying oxygen to the tissues in your body.
- Iron is an essential element for producing hemoglobin, but it is also found in other parts of the body. It's possible to have normal hemoglobin levels but to have low iron.

Canadian Blood Services manages the national supply of blood, blood products and stem cells, and related services for all the provinces and territories (excluding Quebec).

It operates an integrated, pan-Canadian service delivery model that includes leading an interprovincial system for organ donation and transplantation. Canadian Blood Services is regulated as a biologics manufacturer by Health Canada and primarily funded by the provincial and territorial ministries of health. Canadian Blood Services is a not-for-profit charitable organization.

For more information, visit blood.ca.

AAMAC-supported Documentary Debuts

AAMAC congratulates documentary film-maker Jeff Chiba Stearns for premiering his film Mixed Match, about the need for bone marrow and stem cell donors for patients with "mixed" ancestry. AAMAC contributed funding to the film early in its development to help bring attention to the need for donors from diverse backgrounds.

In October, the film premiered at the Vancouver International Film Festival – appropriate given that Jeff is from B.C. and based in Vancouver.

In November it opened at film festivals across North America including the San Diego Asian Film Festival, the Hawaiian International Film Festival, the Philadelphia Asian American Film Festival and the Toronto Reel Asian Film Festival.

As the newsletter was going to print, AAMAC Executive Director Cindy Anthony and newsletter editor Chris Meyer were set to show the Association's continued support for this documentary's important message.

Jeff travelled to openings with Athena Asklipiaeis, founder of the organization Mixed Marrow and the main subject of the film, to answer audience questions. In addition, stem cell drives will be held at each screening for attendees who would like to sign up for their country's bone marrow and stem cell registry. In Canada, that's OneMatch at blood.ca.

According to the film's website, mixedmatchproject.com, "Mixed Match is an important human story told from the perspective of mixed race blood cancer patients who are forced to reflect on their multiracial identities and complex genetics as they struggle with a seemingly impossible search to find bone marrow donors, all while exploring what role race plays in medicine. With the multiracial community becoming one of the fastest growing demographics in North America, being mixed race is no longer just about an identity, it can be a matter of life and death."

One patient featured in the film is Aaryan Dinh-Ali, a Canadian of Afghan/Vietnamese descent with Aplastic Anemia who is currently searching for a donor.

Young Canadian Aaryan Dinh-Ali and his search for a bone marrow donor is featured in the documentary supported by AAMAC. Source: mixedmatchproject.com

Mixed Match Director, Executive Producer, Editor and Writer, Jeff Chiba Stearns.

Jeff is an Emmy® nominated and Webby award winning animation and documentary filmmaker. After graduating from the Emily Carr University with a degree in Film Animation, he founded Vancouver based boutique animation studio Meditating Bunny Studio Inc. in 2001.

From animated viral video ads and broadcast commercials for companies like Sharpie, 3M and Post-it Note, to short and feature films like *"What Are You Anyways?"* (2005), *Yellow Sticky Notes* (2007), *One Big Hapa Family* (2010), *Ode to a Post-it Note* (2010), *Yellow Sticky Notes | Canadian Anijam* (2013) and *Mixed Match* (2016), Jeff's work has broadcast around the world, screened in hundreds of international film festivals and garnered 33 awards. In 2011, he was awarded the Cultural Pioneer Award by Harvard University for his continued exploration of multiethnic identity in his work.

Visit mixedmatchproject.com to find out more and to watch bonus video segments online. And please spread the word about the need for bone marrow donors of all backgrounds – including diverse ancestry – with your circle of family and friends!

Football player donates bone marrow to stranger

This article by Joseph Cattana was originally printed in the Queen's Journal on September 23 and is reprinted with permission.

As Gaels offensive lineman Brendan Ginn walked off the field at Richardson Stadium last weekend, his mother and an unfamiliar face stopped him. It was someone he had planned on meeting for a while now — Kingston resident Joanne Curran.

During this brief moment, the two shared a few words and took a photo while Curran thanked Ginn multiple times.

Although this was the first time the two met, their connection originates from a simple mouth swab that Ginn had done in 2013 that would change the course of his life. It wasn't until two years later that he'd find out exactly how, but Curran's daughter Mackenzie, was the catalyst.

In 2013, OneMatch – a group responsible for finding and matching volunteer donors to patients who require stem cell transplants – was in the ARC, trying to find a donor for then local high school student, Mackenzie Curran.

Curran needed a bone marrow donor after finding out she had myelodysplastic syndrome — a disorder that prevents the bone marrow from producing enough healthy blood cells.

Led by some older Gaels football players, Ginn filled out his email and phone number information, took a swab of the inside of his cheeks with a q-tip and awaited the results.

Later that year a match was found for Curran in Germany. Ginn, hearing the news, moved on from being a potential donor and focused on football. "The odds of finding someone in Kingston is pretty rare, but somebody in the world is going to match you," he said.

And someone did. Although it came two years later, Ginn received a call in February 2015 that changed his life.

"I got a call from a random number in Toronto so I thought I'll answer this and when I did they said 'We're from OneMatch' and I thought oh wow."

While they didn't confirm the details of surgery at the time, OneMatch said they had found a match for Ginn to donate marrow to and they would be in touch.

After four months without hearing back, Ginn thought they found a better match. But in May of that year the same unidentified number showed up on his phone, telling him that he was indeed the best match.

With the surgery set in July of that year, Ginn was prepared to donate the bone marrow from his hip and then to return to football for their preseason. However, after coming down with a bad cold just before the scheduled surgery, Ginn had to move it later, effectively cutting his training camp short.

After telling head coach Pat Sheanan and his teammates about the surgery, his priorities became clear – surgery before football.

Even with hearing stories of people not returning to sport following the surgery, the people at OneMatch put him at ease; telling him the recovery process would take three weeks.

Early in the morning on August 5, 2015, Ginn had two needles drill small slits into his back, taking some 1-odd liters of bone marrow from his hip.

Photo by Julia Balakrishnan

Following surgery, Ginn travelled back to Kingston to get ready for the football season. He spent the first week on the recovery bike and gradually worked his way back to the weights and eventually onto the field. In the end, OneMatch was correct. Brendan Ginn dressed for the first game of the year against the Carleton Ravens.

The surgery was a success, Ginn was able to save a life. Currently, he hasn't met or heard from the person who he donated to. OneMatch leaves it up to the recipient to reach out and while he'd like to meet them, Ginn understands that it's up to them.

Since the surgery, Ginn has been doing what he loves – playing football.

Having both seen the effects of the OneMatch organization, Curran and Ginn decided to meet up to share their stories with each other. It was only then that Curran found out how Ginn's journey began with her daughter that she began to cry.

"Anyone who had swabs and is willing to do it is a hero in her books," Ginn said.

Since meeting Curran on the weekend, Ginn has kept in touch with the family.

After being influenced by older Gaels to take a swab, Ginn has taken the same role. When a team's film meeting finished at Dupuis Hall in Kingston on Sunday, it happened to coincide with a Canadian Blood Services swabbing event at Beamish-Munro Hall. When the team was done learning from the mistakes of their loss to Western, Ginn grabbed a few teammates and got them swabbed.

The bone marrow surgery was a life changing moment for Ginn. "I never thought in my whole life that I would potentially have the chance to save someone else's life or at least give them more time. The fact that I was able to do that for somebody … It's bigger than a lot of us."

CORD Continues to Advocate for Rare Disease Drug Plan

This news release was issued by the Canadian Organization for Rare Disorders (CORD) on October 17. AAMAC is a member.

Twelve years after the Federal, Provincial and Territorial Health Ministers committed to developing a plan for rare disease drugs, patients are standing outside the site of the annual Health Ministers' meeting in downtown Toronto asking, "When will you deliver on the promise?"

Back in 2005, dozens of families affected by rare diseases, demonstrated for two days outside the Health Ministers' Annual Meeting pleading for access to life-saving therapies for two specific conditions. The Ministers agreed to fund the drugs and also to develop a national plan. They made good on the two drugs, and today every one of those patients at the demonstration is alive. But the national Drugs for Rare Diseases plan never materialized. And the fall-out has been devastating.

According to Durhane Wong-Rieger, President of the Canadian Organization for Rare Disorders, "The lack of an access plan means that almost every time there is a new rare disease therapy, patients and families often send out pleas through Facebook and Twitter, appeal for support through newspaper and television, and lobby the politicians." Because many conditions are severe and progressive, many patients deteriorate and some even die waiting for access to a drug that is already approved by Health Canada.

A disease is considered rare if it affects no more than 1 in 2,000 persons. But, because there are more than 7,000 rare diseases, altogether there are about 2.8 million Canadians with rare diseases, and 60% of them are children. About 40% will die before their sixth birthday.

Today, rare disease patients and caregivers are demanding that the federal government immediately implement the Orphan Drug Regulatory Framework. It has been 34 years since the USA and 17 years since the European Union passed their Orphan Drug Acts. Canada is the only developed country that does not have orphan drug legislation to support research, drug development, and clinical trials.

The Health Ministers have known about Canada's Orphan Drug Regulatory Framework for three years. On Rare Disease Day (February 29th), all the Parliamentarians wore the yellow scarves symbolizing their support for rare diseases, so CORD is asking, "What is Federal Health Minister Philpott waiting for?" Canadian lives are literally at stake.

Rare disease patients, families, and friends are gathering outside the Health Ministers' meeting at the King Edward Hotel in Toronto, hoping to get answers to their questions.

CORD Campaign in Ontario

CORD posted the following Ontario information on its website, raredisorders.ca.

Support MPP MacLeod's Private Member's Motion on a Compassionate & Catastrophic Care Program

Lisa MacLeod, MPP (Nepean-Carleton) is bringing forward a Private Members' Motion on October 20th, to address the funding gap for patients in exceptional circumstances through the consideration of a compassionate catastrophic care fund.

The motion reads:

"That, in the opinion of this House, the Ministry of Health and Long Term Care (MOLTC) appoints an advisory committee to review jurisdictions where a process is in place to consider lifesaving experimental and high cost healthcare treatments and otherwise exceptional circumstances for patients. The MOHLTC advisory committee should consider Australia's Special Access Scheme; New Zealand's Exceptional Circumstances Framework and High Cost Treatment Pool and the UK's National Health Service's Experimental and Unproven Treatments Policy with the view to establish a compassionate catastrophic care program in Ontario for those suffering from rare disease or whose treatments may be experimental or complimentary but are not yet covered by Ontario Health Insurance Program (OHIP)"

What you can do to help:

1. Send a letter to your MPP and ask them to support the motion
2. Please RSVP to info@raredisorders.ca if you or anyone from your group is able to attend the press conference on Thursday, October 20 at 1 pm at the Queen's Park Media Studio, followed by the debate in the gallery
3. Please let us know if you or anyone from your organization would be interested in sharing their story with the press and the issues they have faced.

Mark Your Calendars

Please also check local provincial updates for regional support group meetings and education events.

For further information about events, call the office toll-free at 1 (888) 840-0039 or contact info@aamac.ca.

Annual Patient Education Day
Mark your calendar! AAMAC's next annual Education Day is headed west and will take place in Vancouver on September 30, 2017. Watch the newsletter and website for more details about it and other meetings.

You can also like AAMAC on Facebook.

News of Note

New! AAMAC's Question Corner
At AAMAC's recent annual Education Day, participants get a chance to ask healthcare providers general questions about bone marrow failure diseases. We'd like to offer the same opportunity in the newsletter.

If you have a question, please let the office know and we'll ask an expert for a response. We won't include your name so you can ask without sharing personal information in the newsletter. Please keep your question general as medical professionals cannot offer specific advice without having access to your detailed medical files. We'll try to include one Q&A in every issue if there is interest.

Aplastic Anemia Makes Blacklist
The character Alexander Kirk, played by Ulrich Thomsen on the television show The Blacklist, was recently diagnosed with aplastic anemia and in need of a bone marrow donor.

Strength in Numbers
The Aplastic Anemia and MDS International Foundation (AAMDSIF) announced its merger with the PNH Research and Support Foundation (PNHF) on January 1, 2017.

According to the announcement, since 2013, AAMDSIF and PNHF have been strategic partners in helping patients with PNH. The partnership allowed AAMDSIF to perform all administrative duties for PNHF, enabling that organization to focus on patient services. With the merger, the expenses that were being spent on mission core support services will now be dedicated to patient services and research. PNHF committee members will be an integral part of the implementation of this merger and remain pivotal to the ongoing patient advocacy program.

The activities that have defined the PNH Foundation – such as online chat, the PNH walk in New York City, and the travel assistance fund – will continue. "These key functions are critical to supporting and connecting with our PNH patients," says Kathleen Weis, CEO of AAMDSIF. "We plan to continue and expand those services as we move forward."

The Aplastic Anemia and MDS International Foundation (AAMDSIF) has been arming patients and families with the information they need to fight bone marrow failure disease since 1983. The organization sponsors innovative and collaborative research through the MDS Clinical Research Consortium and with its own research grant program. Based in Bethesda, MD, the Foundation has received Charity Navigator's four-star rating for 11 consecutive years.

Platelet Podcast for Healthcare Professionals
Canadian Blood Services recently posted a podcast and blog by staff science writer Jenny Ryan about platelets. Called "Platelets Unplugged: The Sticky Truth," the podcast was developed with the International Collaboration for Transfusion Medicine Guidelines (ICTMG) and American Association of Blood Banks (AABB).

The podcast is moderated by Dr. Richard Wells, a hematologist with Sunnybrook Health Sciences Centre, co-director, myelodysplastic syndromes program, Odette Cancer Centre; and Chair of AAMAC's Medical and Scientific Advisory Committee.

CBS says this is the first in a series of podcasts digging into best practice for the transfusion medicine community and health-care professionals. The Sticky Truth focuses on two new platelet transfusion guidelines recently published by the AABB and ICTMG. It features Dr. Richard Kaufmann of the AABB and Dr. Susan Nahirniak representing the ICTMG.

Visit blood.ca/blog to check it out.