

Fall 2010

OPEN ARMS

Newsletter

Open Arms has seen many changes over the past year, both internally and externally. We recently completed our 2nd Annual Fundraising event. The event was a great success, with 120 people in attendance. Open Arms volunteers and clients helped to make the event memorable and educational. Dinner with live jazz music set the stage, and a successful silent auction helped raise funds for our organization. We also held our Annual General Meeting, which is always a valuable opportunity to look back over our progress as a not for profit organization, our forward motion as an advocating agency and a partner and resource for both our community as well as Alberta Health Services.

Open Arms celebrated its third anniversary on March 24th, 2010, and we wish to share the many changes, challenges and opportunities for growth that we have experienced.

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Open Arms Patient Advocacy Society
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PO Box 29007 Hidden Valley RPO, Calgary, Alberta, Canada, T3A 6L2

A Word from Our Board of Directors

The Open Arms Board of Directors has had a busy year, focusing on a number of new initiatives. Open Arms has grown incrementally over the past few months, both in the number of referrals, the advocacy role, the demand from media for involvement and from Alberta Health Services as they develop their new mandates and direction. As a result, the Board of Directors has moved toward a strong professional board, consisting of a combination of patients, social workers, a lawyer, and medical professionals. The board has also developed a high level of accountability with regard to operations, community involvement and patient response. Our goal over the next 12 months is to align all policies and procedures with the strategic plan and to ensure that operationally Open Arms is a timely, responsive and strong advocate and partner to those that we work with. Our Board currently meets on a regular basis with 9 or 10 scheduled meetings annually.

Our current Board of Directors consists of 12 Directors and the following advisors:

Chairperson: Rick Lundy
ri_lundy@openarmsadvocacy.com

Co-Chairperson: Linda O'Donoghue
li_odonoghue@openarmsadvocacy.com

Co-Chairperson: Deb Runnalls
de_runnalls@openarmsadvocacy.com

Treasurer: Penny Thiessen
pe_thiessen@openarmsadvocacy.com

Board Secretary: Jill Smith
ji_smith@openarmsadvocacy.com

The Board of Directors of Open Arms is actively involved in the organization. The Board currently has 8 active committees, each of which is chaired by a member of the Board of Directors. The following are the committees and their respective chairs:

Advocacy Committee: Rick Lundy
ri_lundy@openarmsadvocacy.com

Fundraising Committee: Linda O'Donoghue
li_odonoghue@openarmsadvocacy.com

Technical Committee: Joe O'Donoghue
jo_odonoghue@openarmsadvocacy.com

Media Relations Committee: Rick Lundy
ri_lundy@openarmsadvocacy.com

Membership Committee: Sue Adams
su_adams@openarmsadvocacy.com

Women's Health: Christina Hendra
ch_hendra@openarmsadvocacy.com

Mental Health: Avalon Roberts
av_roberts@openarmsadvocacy.com

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Volunteer Committee: Jill Smith
ji_smith@openarmsadvocacy.com
Communications Committee: Brenda Rawcliffe
br_rawcliffe@openarmsadvocacy.com

For more information about our Board of Directors, please visit the director profiles section of our web site.

Updates from our Board Committees

Our Board committees meet on a regular basis as scheduled by the Chair of each committee. Updates from our most active committees follow.

Our Volunteer Committee

The Volunteer Committee was created in September of 2009. Since then, it has recruited for 6 volunteer positions and had 18 people attend orientations. We have successfully placed volunteers in various committees and had one volunteer move onto the Board of Directors.

Our Advocacy Committee

The Advocacy Committee has been very active since our last newsletter and we are going in a direction that is both exciting and challenging. We have lost two of our advocates and we are in the process of training two more individuals to add to the Advocacy Committee. If you or somebody you know would like to find out more about becoming an Advocate please contact Jill Smith at ji_smith@openarmsadvocacy.com. Open Arms currently has 110 active cases, 37 of which involve deaths. Our case load includes cases from Neurology, Cardiology, Women's Health, Senior Care, Infectious Diseases, Emergency Room, Mental Health/Addictions and complaints against Physicians or Nurses. We also have 14 cases that include individuals that cannot get the proper medical attention that they require. Therefore, we are assisting them in navigating through the system to get them the help that they require. The Advocacy committee has been working with Alberta Health Services (AHS) in developing policies regarding how AHS and Advocacy groups, such as Open Arms, work together to ensure the patient gets the best possible interaction from both organizations. Basically, the policies set out the rules and guidelines to ensure both organizations understand the framework when interacting with one another. This is a huge step for Open Arms and AHS as there has not previously been anything similar and these guidelines will ensure consistency that will benefit our clients, AHS and Open Arms. A special thank you to Chantal and Deanne Durand who volunteer and work extremely hard for this Committee and their contributions have made a considerable impact in the success of this Committee.

Our Membership Committee

The Membership Committee coordinates and tracks membership in Open Arms. We currently have 161 members with 68 active members. Members are notified on their renewal date via email.

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The annual membership of \$10.00 furthers our abilities in providing advocacy services for our clients. As well, having a database of Members is crucial to backing up our organization and what we stand for with regards to liaising for changes with government and other bodies in relation to Health Care Services.

If you know anyone who would be interested in supporting our organization and becoming a member, please forward the applicable fee to:

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Thank you for your support and any additional donations would be greatly appreciated to help further our cause. Your help IS making a difference.

Our Mental Health Committee

It is an exciting time for Open Arms as we begin the creation and implementation of our Mental Health Committee. As we have worked with supporting patients facing adverse medical events and/or their family members, we have seen a consistent pattern of mental health issues often overlapping with the medical issues. As a result, many patients do not receive the support and medical response required because the mental illness presents as a barrier and can interfere with the medical treatment offered. Delving into the issue of Mental Illness has been identified as a high need from the perspective of many of our patients, the community and medical professionals. This exciting undertaking will be the beginning of new community partnerships, an opportunity for Open Arms to take a leadership role in the area of mental illness and the development of accountability from the medical profession within the realm of mental health.

The Mental Health Committee has begun development of the committee direction. The impact statement, a work in progress, is “To bring to the forefront the voices of individuals and families who have been impacted by Mental Illness”. This group has now begun the task of gathering information on resources, other mandates serving this population and statistical data to better set direction, avoid duplication of service, identify potential partners and ensure that an unaddressed need is met by this committee

Our Women’s Health Committee

We have recently added a Director to our Board who will be chairing the Women’s Health Committee. This area has been very inactive for some time. However, we have recently had some concerns in this area with privacy issues in emergency and the length of time it takes women to have a D & C procedure. These are issues that this committee will be looking at and providing AHS with our concerns and recommendations for improvement.

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Our Fundraising Committee

The fundraising committee recently held our second annual Silent Auction and Dinner Event. The evening was very successful in sharing information about the work Open Arms does and in raising funds for our cause. Some highlights from the evening were our 3 guest speakers. As clients of Open Arms, our guest speakers shared their very difficult and personal experiences in dealing with the Health Care system and how Open Arms assisted them.

We thank all the donors, volunteers and our guests for the evening, as well as the Inglewood staff, all of whom helped to make the evening possible.

The committee is hoping to hold more events in 2011, such as a Bingo fundraiser and another dinner event. We look forward to your continued support!

Community Initiatives

This year Open Arms was asked to sit on a number of focus groups and facilitation committees as a partner with Alberta Health Services. Below is our submission to the MLA review committee on the New Alberta Health Care Act.

July 8, 2010

Mr. Fred Horne, MLA
Edmonton Rutherford
Lansdowne Shopping Centre Suite
102, 5124 – 122 Street
Edmonton, Alberta
T6H 3S3

Re: Alberta Health Care Act Submission

Dear Mr. Horne, MLA:

On behalf of the Open Arms Patient Advocacy Society, I would like to thank both yourself and the advisory committee on the Alberta Health Act for the opportunity to offer input both in person and through this submission on the new Alberta Health Act.

This time of change and transition has the potential to be one of positive motion toward more client-centred and accountable health services in Alberta. The development of new legislation, policies and practices and operational response are all potential for Alberta Health Services to not only respond to the needs of Albertans in a way never before seen, but also to lead the way through Best and Promising Practices to health care second to none in North America and certainly within Canada. This is an opportunity to rise as leaders in the provision of Health Care to all Albertans.

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Aligning with this potential for positive change also lie many avenues into potentially negative outcomes as the Alberta Health Act is delivered. Being aware of the potential for disadvantageous outcomes is the opportunity to not only prevent but ensure that this Act is developed and implemented with knowledge and awareness of all avenues for potentially positive and negative outcomes and thoughtfulness with regard to the consumer who is the patient.

Open Arms represents patients who have had, or perceive that they have had, an adverse medical event. Although many patients have suffered, or their loved ones have suffered, serious and often life-threatening medical events, most are not seeking support in initiating legal action against Alberta Health Services and/or its representatives but rather are seeking answers and an opportunity to be heard. Most want to know that what they have experienced is used as a learning opportunity to ensure that similar events do not occur to others. As a result, Open Arms has the advantage of working with people who carry much of the information needed to develop policies, procedures, responses and to remain current with what the community perceives that it needs from its medical system.

I will list categorically the points that Open Arms wishes to offer to Mr. Horne and the committee:

- 1) Patients cannot follow a rights and regulations patient charter if they do not understand what those rules, rights and expectations are. Very rarely is a patient involved in the medical system for a positive reason; as a result the assumption that they are under some stress, are uneasy being involved in a large bureaucracy that they do not want to be involved with and do not understand or trust and they are operating under the assumption that they have little to no say or input into what is about to occur is, in most cases, quite accurate. As a result, the medical practitioners and the medical system must be designed to create opportunity for the patient, at any point, to clarify their part in the system, to seek answers to any questions they may have and be invited to be involved in this, their medical treatment.

A patient charter (called such to connect the patient to the process and the document, rather than an impersonal 'health charter) must be designed with the patient in mind, not the medical system. It must be easily read, easily understood and must speak to all members of our society. We are a diverse community, and as such, our aboriginal, immigrant and refugee, poverty stricken, addicted, mentally ill or other potentially barriered members must be invited into this process in a way that speaks to who they are, not who a medical system wants them to be. Also this Charter must speak to urban, rural and isolated communities in a way that not only supports them as a unique entity but also unite them with the other centres which, from time to time, patients may have to access.

- 2) The community will not feel as though this is *their* medical system, one that they are involved in and have any voice in, if they are not invited to be partners. The act of 'doing with' rather than 'doing to' is one that can make or break any relationship, and engagement of the community is a critical piece in building trust, tearing down barriers and maintaining a relationship that will benefit both parties as we move forward with this Act. On-going community focus groups are a critical piece in building a collaborative and involved relationship.

It is also imperative to ensure that these groups are welcoming, presented with the audience in mind. They should be informative, well lead and the participants must be reassured that there will be notes of all feedback taken. People have busy lives, taking time out for a forum such as this must serve to reassure that their attendance matters, their voice will be heard and all feedback is reviewed by an appropriate body.

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Keeping the audience in mind is the critical first key in ensuring that the participants are engaged appropriately. You will not hear from the homeless unless you approach them through trusted sources and ensure that the process is presented in a forum and environment that they are comfortable with. Seniors were raised in a culture of not questioning the medical system and therefore would benefit from being approached in a manner and framework that would encourage them to see their medical care in a new light. Aboriginal peoples must be reassured that these forums are about them and to benefit them and to improve their medical care. If each forum were personalized according to the audience, had clear goals and agendas and ensured that the community felt respected and heard would all have the potential of turning this Act into a successful health care system, long term.

- 3) Adverse medical events are a reality of delivering a system of care where every situation is different, there are multiple players and the outcomes are never easily predicted. As a result, any legislation, policies or charters developed would do well to speak to this potential risk at the outset. Opening the door to the conversation builds trust, creates an environment for conversation between the patient and the medical system, educates both parties to the precarious nature of medical care and ensures that the Alberta Health Act does not hide behind its own legislation, but rather willingly and in a forthcoming manner addresses all issues, real or potential.
- 4) The intimacy between communities and the smaller Health systems of the past cannot be lost if this new Alberta Health Act is to be successful. Relationships once strong between the medical system and the community have been lost due to the restructuring, changing of positions internally and the resulting media coverage, and the transformation of the Health Care System to a super board, which appears from the outside to be intimidating and unapproachable. There must be a concerted effort to reengage the community; stakeholders, partners, collaborators and those who offer medical services outside of the realm of the Act are all key players and impact the success of this Health Act. These partners have the potential to tear down barriers and be a critical link between the health care system and the public.
- 5) Accountability to the public is critical. The community must buy into this being ‘their’ medical system, and as a result, constant community feedback (through the forums) is imperative, but also through patient and family experience. The patient is the truest measurement of whether the system is working or not and the patient is also the one to guide the Health Care System in strategic planning for the future.

Timely and honest reporting to the public is necessary in ensuring that the community feels as though there is accountability that is authentic and genuine, addressing not only those services, statistics and outcomes that show how well the system is working, but also addressing system weaknesses, issues and concerns, adverse medical events and most importantly the way these are being addressed. Community reporting will create an environment of transparency and integrity and also hold the Health Care System accountable for always monitoring itself and responding in a timely manner to any issues or concerns.

- 6) The community needs to understand who and what their Health Care system is. A visual organizational chart, easily read, clearly presented and designed with all partners in mind, would ensure that:
 - a. The community understands their health care system
 - b. Community members know the hierarchy and therefore can make educated decisions about who they need to speak to

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- c. Community partners and stakeholders shown on the chart would present to the community a system that is not working alone, but rather as a member of the community itself
- 7) All communication from Alberta Health Services to the community should not be written from the perspective of what AHS wants the community to know, but rather what the community perceives it needs to know. Long, complicated and ‘legalese’ documents alienate and disconnect the reader from the information. Clear, simple and welcoming documents encourage the reader to not only get through the information offered, but to feel connected to the information shared. If a patient or family member cannot be bothered, in a time of illness or crisis, to read through the information that they need to know, they are not best prepared to make educated decisions, respond appropriately to what the medical system requires of them, or to even engage in receiving medical care. This must be patient centred, not Alberta Health Services centred.
- 8) Alberta Health Services staff, regardless of which roles they are in, are often the bearers of bad news, the first responders to critical illness, the first to speak to family in a time of crisis or loss and the face connected to the medical system. As a result, they must be educated in the many faces of trauma and crisis. They must know that this is not about them; the people they are working with are vulnerable and hurt and grieving and afraid. They must be supported in debriefing, processing and constantly offered opportunity to be human and to vent their own emotions. This is the only way that they will be able to face what they do day after day without personal cost.
- 9) The various systems that feed into the medical system must be offered funding to ensure that their students, staff and collaborators are always up to date, educated in this diverse system and aware of the dynamics of the Alberta Health Care Act. Students from nursing, social work, doctors, justice and security and even the administrative and operational staff (housekeeping, stewards etc.) must be well educated in the expected treatment and care of a patient, the culture of the Alberta Health Care Act and the Act itself. This consistent understanding of the Legislation builds a united workplace, uniform care from all medical system members and accountability that does not deviate regardless of role within the system.
- 10) Access to medical records is a critical component of ensuring a patient’s trust of the medical system and offers an opportunity for a patient to truly feel in charge of their medical care and treatment. In the event that there is an adverse medical event, if there are questions or concerns, or if another system is involved (i.e. child welfare) and the file is required, a complicated and difficult system to navigate to access the file can cause the patient to feel as though Alberta Health Services is withholding the file or intentionally creating barriers to prevent full disclosure. The opportunity for Alberta Health Services to be a collaborative, transparent and supportive partner with the patient through ensuring smooth receipt in a timely manner of the patient file is a critical step to building a strong relationship with the community based on respect and response.

Open Arms Patient Advocacy Society has historically been a strong partner with the health care system. We are honoured to be invited to partner with Alberta Health Services in ensuring quality, responsible and patient-centred care and look forward to future opportunities to support Alberta Health Services in the development, introduction and implementation of this legislation and Act to all Albertans.

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Sincerely,

Mrs. Deb Runnalls, RSW
Director, Open Arms Patient Advocacy Society
(403) 830-5035
elpis3@telus.net

*On behalf of the Board of Directors of Open Arms,
We thank you for your continuing support.*

*Remember, it is organizations like Open Arms
that will force changes and improvements to the
Alberta Health Care System.*

*Thank you!
The Board of Directors
Open Arms Patient Advocacy Society*