Welcome to Health Arrows

We created this information site for three main purposes.

First, it is to provide you with knowledge based on our personal experiences with the Health Care *System* in Alberta. Knowledge that could mean the difference between life and death for you or someone you know and care about when you have to rely on the health care system in Alberta. We firmly believe that if we would have had this information in advance, Greg, our son, brother, friend, would be with us today.

Second, it is to provide you with the knowledge which will help put you in a position to support the critical change so overdue and necessary to the patient care system in Alberta. Currently, as you will learn reading what we are recording on this site, there really is no ***system*** for patient care at all. Well-meaning and knowledgeable people inside the health care world have tried for many years in the past and some continue to try to make the needed changes without meaningful success to date. The only way the kind of change needed will occur is if the public is properly informed of the terrible and unnecessary losses happening inside the so called health care system and ensure change occurs, the sooner the better. Lives depend on it.

You may wonder why you have not heard publicly about these kinds of incidents and tragedies before now. We believe there are a few key reasons. For the families involved, it is very, very tough, basically impossible to make the decision to talk publicly about their loss. Investigations take a long time and often, even if there is the desire to get the word out, the media is likely to feel it is too old for news or coverage. It is also the case that almost all investigations are done within the "system" and are not made public for a variety of reasons, not the least of which is the protection of the medical professionals involved.

Third, we hope that our Health Arrows, that an active, informed and hopefully growing group of the public can really become strongly engaged and make some huge changes to the way care is willingly provided to patients here. The current situation serves no one well.

The "system" should be *continuous, collaborative, patient centered.* None of these characteristics exist or are system wide today. Individual doctors, and indeed even a few clinics try to work this way, but all have to rely on other suppliers of services or expertise and these are not organized to function to be continuous, to be collaborative and many are not at all patient centred. We believe that everyone should test not only their own interface with the health care system against these critical characteristics but also to use them to guide us all in the pursuit to drive the necessary and critical change.

Greg's tragic loss is the first case to be reported. We intend to add some others as well, that we will have been provided by others who also want to share their experiences with you for the same reasons: People like us who want to have you benefit from their experiences and be better prepared to aggressively support your individual pursuit of care in the system, and to have you more informed and able to help support the change you believe needs to occur within the health care system in Alberta.

The information provided here was written in May 2013 and is based on the facts as we know them, and our beliefs of the circumstances surrounding those facts. This document (in it's entirety) was provided to the organizations who were interested in pursuing their own investigations into Greg's case. The cases reported will be updated when and if new information is provided and as new reports are completed.

You are encouraged share this information with your families and your friends. Everyone is welcome to utilize this information for your own personal use but it is prohibited from use in any form, in the pursuit of personal or corporate financial gain.

We are not doing this to bring attention to ourselves and we do not want any. What we want is to prepare those of you who are interested, for the time(s) that you may find yourselves dealing with the health care system here.

The names of the doctors and caregivers involved have not been provided in these cases. The purpose is to inform you of the kinds of circumstances and the kind of decision making done to deal with patients (*rather than decisions made **with*** patients) that is occurring. It is not to identify specific people. The core of the problem is not any specific individual but a pervasive culture of individualism, and of arrogant complacency rather than collaboration for each patient's continuous care. Again, there are individual doctors and care givers that do the best they can however the task of continuous, collaborative patient centered care is much more than one person can provide.

One man's journey to his premature and tragic death in the Alberta Health Care "*System*"

Greg's case.

Day 1 of concern ("c" notation by day number)

> Greg was a 30 year old athletic, fit, Mechanical Engineer and private pilot when he expressed some concern about one of his testicles to Doctor #1 during a routine medical examination. Doctor #1, who happened to have some experience with patients with Testicular Cancer, initiated a series of tests and on completion, explained that the test results did not indicate a problem at that stage but it would be important to monitor it closely and on any indication of change, come back to him and in any event, check back in a year's time.

Day 284c

> Greg had developed a rash on his feet and went to a convenient walk-in clinic and met with Dr. #2 to get it identified and treated. Dr. 2's recommended treatment later turned out to be unsuccessful.

Day 308c (Day 1 of action on potential cancer, "a" notation by Day number)

Greg returned to Doctor #1 to seek his assessment and help for the foot rash problem and at the same time, his testicle was examined. At this point, Doctor #1 felt that Greg should be examined by a specialist and Dr. #1 wrote a letter referring him to Dr. #3. He also asked Dr. #3 if a biopsy should be taken. It was assumed by Dr. #1 that this would take place relatively quickly and when Dr. #1 heard nothing subsequently, he mistakenly assumed that the examination had gone ahead and there was nothing to be concerned about. Dr. #1 did provide good advice to Greg with respect to his rash and it receded over the coming weeks.

Dr. #3's office did not contract Greg until 93 days later. Curiously, this coincidentally was the day Greg finally attended an appointment with a surgeon, and 2 days before surgery and 6 before his death.

***Lesson #1**, Never assume that when a referral is made to another doctor, that the case will be treated with any particular priority. At this point we don't know why it took 93 days before the requested contact was made to Greg by Dr. #3's office. We also don't know why, if it was going to take this long, Dr. #3 didn't simply advise either Greg or Dr. #1 that he couldn't/wouldn't see Greg in any reasonable time so that someone else could respond appropriately. We believe a response in weeks, not months, would have meant Greg would have been in a much better position to go through the surgery and to survive treatment and continue his life.*

Day 347c -39a

Greg was not someone who brought attention to his own health and had only very rarely gone to seek treatment for any health concerns in the past, but he began to suffer from some back and abdominal pain. Initially he thought it was the result of some pulled muscles that happened while weight training and then wondered if it was the result of a collision on the basketball floor when he played in an Alumni Tournament. Greg went back to the walk-in clinic that was on his drive to work and Dr. #2 examined him and ordered some tests including an ultrasound scan of his abdominal area.

Day 355c-47a

An ultrasound examination done on Greg showed images that were not completely clear but did identify an abnormal mass in Greg's abdomen. Specialist #4 reported in his notes that he talked to Greg about this mass and it was his opinion that it was putting pressure on his IVC (inferior vena cava) and that it was suspicious for a form of cancer. Specialist #4 noted that "the patient requires urgent further assessment with CT chest, abdomen, and pelvis to characterize findings further."

At approximately 2:00 p.m. Day 355c- 47a

Specialist #4 noted that he discussed the findings by telephone with Dr.#2.

Greg also underwent a chest X-ray by Specialist #5 on Day 355c-47who noted the mass.

Day 361c- 53a

Greg met with Dr. #2 and discussed the tests, their ramifications and the need for a further examination with an urgent CT scan, which would more clearly show what was in Greg's body cavity.

Day 362c-54a

Dr. #2 Wrote the urgent request for the CT scan on Greg and had it faxed in to Calgary.

Day 363c-55a

Greg turned 31 today. After work, he stayed in and visited with his sisters in the city. His mother and I unfortunately were away on a previously long planned 10 day holiday. One that we had invited to Greg to come on and he had declined, citing work and his desire to improve his own financial position with his business. Clearly we now deeply regret being away during this very critical time.

Day 381c-73a

CT scan gets done in Calgary nearly 3 weeks after the "urgent" request.

Lesson #2 "*Urgent" in the health care system doesn't mean urgent! It is very difficult for us to understand now (and I am sure Greg at the time) how something classified as urgent takes 19 days to become acted upon. "Urgent" to the radiologist meant not only sending his report but personally calling the doctor that requested the tests the same day he made sure the information was communicated to the doctor examining Greg's health. The "system" took 19 life draining days to react but the radiologist acted within hours.*

In our investigations months after Greg's death, we were told by other well respected doctors that times approaching three weeks after an "urgent request" is made is not uncommon. In fact it was classified as "normal". It was explained that it is in part because many doctors classify their requests as urgent to try and move up the waiting list. We also were given the impression that because it was normal, we shouldn't expect anything more and it was not the fault of the system that led to Greg's death. Clearly the system is broken if the necessary resources are not available on a priority basis, related to the patient's real critical needs. The fact that doctors are not working within a disciplined process of prioritization is bad news, but the worst part is the system position that because it is "normal", it is ok, regardless of potentially deadly outcome.

Day 388c- 80a

For about a week, Greg waited for follow up by Dr. #2 but it didn't come. Finally, he called back to the clinic and learned that Dr. #2 was no longer there and had taken a different job at the University of Calgary. Greg asked about his file and who was taking care of it now.

Lesson #3 *Never ever assume that there will be the critical smooth hand off between doctors, or that the doctor treating you has your best interests as his first priority. Greg had to follow up himself to find out what had happened after "his doctor" did not communicate with him as Greg expected during this critical time. While we don't know to what extent Dr.#2 made any effort to ensure Greg got the continuous attention that was absolutely critical at this time, the fact remains that there was a week gap and the only way there was re-engagement was after Greg made the calls and caused it himself. This is clear evidence that Dr. #2 simply didn't do enough. Every day the cancer mass in Greg's abdomen was growing rapidly. Every day that passed made Greg's situation worse. We don't know how many of Dr. #2's patients were abandoned in the same fashion as Greg was, but we do know too well that one was too many.*

Day 390c-82a

Dr. #6 consulted with Greg and explained what he thought was the most likely cause of the growth in Greg's abdomen. He believed it was testicular cancer that had moved to his lymph nodes and was rapidly growing in his abdomen and putting pressure there and also causing the pain that Greg was having in his back. Dr.#6 said that he would refer Greg to a specialist doctor in the relatively new and highly publicized centralized Urology Centre in Calgary. This specialist would examine the information and be able to interpret and confirm exactly what the mass was. Greg was told to expect a call from this doctor within a few days.

Day 398c-90a

After more than a week passed without contact from anyone at the Urology Centre, Greg called back to the walk-in clinic to find out what was happening. There the woman that answered the phone told him that they had not heard from Dr. #7 at the clinic either and perhaps Greg should call Urology Centre to speak to Dr. #7 himself.

Lesson #4 *Do not assume when a doctor is aware that a colleague has failed to insure continuous care that he/she will make an effort to prevent this mistake from happening again. It is incredible that on top of Dr.#6 not having a system to follow up with the referred to Dr. #7 himself, his staff simply told Greg to do his own calling. This is an indication of a poor (and dangerous) attitude toward patient care.*

Day 398c-90a

Greg called the Urology Centre for Dr. #7 and got a taped message explaining that Dr. #7 was not in the office and wouldn't be returning until a date, still a couple of weeks away. There was no method of leaving a message there so Greg called back to the walk-in clinic yet again and told

them what he had learned himself. They told him they would follow up again. (All this time Greg was feeling increasing pain and we later learned that he had been going to the freely available blood pressure machines in pharmacies to check and was seeing his blood pressure increase. Clearly Greg's own concerns were increasing.)

Day 399c-91a

Greg got a telephone call from a secretary at the Urology Centre indicating that Dr. #8 had an appointment available to see him on Tuesday (Day 403c-95a)

Later the same day, Greg got another telephone call from the Urology Centre indicating that Dr. #9 had an appointment to see him on (Day 402c-94a) Given that this appointment was a day earlier he confirmed that he would attend the appointment with Dr. #9.

Lesson #5 *If you are referred to the Urology Centre located next to the Rockyview Hospital in Calgary, do not assume that this is a centre where a team of doctors work together to give patients the very best care they can. They don't work as a team and indeed, they don't even communicate with each other well enough to know how an individual patient fits there. The "don't call, us we'll call you" approach and the avoidance of collaboration at this specialist clinic was our first and worst experience, but later encounters confirmed that this is, in fact, is the culture there.*

Day 401c-93a

Up to this point in time, Greg had only informed us, his family, of the generalities of the pursuit of the cause of his back pain and more recently, of his difficulties in making progress through the system with the doctors in it. He had consistently resisted providing us more details or the opportunity to help him with this. We had encouraged him to be more aggressive in his expectations of responses from the system and when we learned that he had finally got an appointment with a specialist who would be able to provide him with answers, we asked if we could accompany him to this appointment. Initially he said no but his Mother pressed harder and Greg agreed that we could go with him to this appointment. It was only after this decision that Greg went ahead and explained what he thought the situation was. He explained that he had done extensive research on the internet into testicular cancer and its two main types. He had learned that it was one of the fastest growing forms of cancer and while this was a concern, it also made it most susceptible to chemo therapy treatment with a relatively high success rate. He also said that there was doctor in the U.S. that had developed a surgical technique that removed the cancer in certain cases. While this was a very major surgery, if the chemotherapy wasn't successful, this kind of surgery would be necessary in the end anyway. The process was much quicker and it reduced the need for and the level of chemotherapy necessary.

Of course learning what Greg had now told us was a tremendous shock. In addition to making us very anxious about the days ahead, it also changed how we viewed the past. We now felt we

could have been more supportive both to Greg while he had chosen to deal with all of this on his own (keeping it from us because he didn't want us to worry unnecessarily) and also to have been active ourselves in trying to get the care and priority he should have been given by the health care system.

Day 402c-94a

Greg (accompanied by his Mother and me, his Father) attended the appointment with Dr. #9 and I went in with Greg to the examination room. Dr. #9 indicated he had reviewed Greg's file and after a brief examination of Greg's testicles and his abdomen, indicated that he was 99% sure that it was testicular cancer. He stated that he would like to surgically remove Greg's affected testicle and then he would refer Greg to an Oncologist at the Tom Baker Centre where he would undergo chemotherapy to shrink the mass in his abdomen. Dr. #9 noted that the back pain was being caused by the rapidly growing mass in his abdomen and the elevated blood pressure (which Greg noted occurred in the last 2 weeks) and the swelling in his legs was due to the pressure on his inferior vena cava (IVC) slowing his circulation. Dr. #9 said he would prescribe some stronger medicine for Greg to use for his pain.

When Greg asked about the alternative approach with surgical removal of the abdominal mass, Dr. #9 essentially dismissed this approach touting the credentials of Urology Centre and the doctors there. He explained that they treated many patients the way he explained, with success. He joked about Greg not going to die and related a situation about a classmate of his surviving a cancer case like Greg's 20 years ago. Dr. #9 did go on to explain that if surgery was needed to remove the mass, the person in the Urology Centre who would do that surgery was the fellow whose name we recognized as Dr. #7.

Lesson #6 *Do not let a doctor smooth talk over your concerns but be very tenacious in making sure that you understand completely how every one of your concerns is going to be dealt with. I didn't think about it at the time but clearly Greg was increasingly concerned with his discomfort and rising blood pressure. While he never said anything to us, I now believe that the reason he was considering the much more major surgery in its early stages of development in the U.S. was his concern with the size and growth of the mass inside him and worrying about how fast things were getting worse. The major surgery would have removed it and not left it to continue growing to be treated later. We also can't help but wonder if Dr.#7 had actually been the first doctor to see Greg at the Urology Centre, whether he would have chosen the same path as Dr. #9 or whether he would have made the decision to cut out the circulation robbing massive growth right away.*

Dr. #9 also talked to Greg about the fact that some patients, in this circumstance, actually put some of their sperm in a sperm bank, so that it would be possible to have a family in the future, if the chemotherapy negatively impacted the remaining testicle. He explained that it would be difficult for Greg to work full time during the treatment which indicated to us that he didn't

expect it to be as tough as we thought it would be. We expected Greg to be off work completely for some of the time.

Dr. #9 explained that he would have a woman in the office do the paper work with Greg for the upcoming surgery. He had kept a spot open for the surgery in 2 days and the office would confirm the exact time as soon as it was scheduled. He also explained that they would do the work with the Tom Baker Centre to have it all set up for him to go there next to undergo the chemo treatment. This treatment would follow confirming the specific type of cancer from tests on some of the tissue from the removed testicle, and the creation of the treatment plan for this type of cancer. Greg was told to expect a call from the Tom Baker centre the day after the surgery.

Dr. #9 left and the woman in the office came in and Greg provided her with the necessary information and he signed the forms where expected.

On the way home, the three of us discussed what we had learned and our impression of Dr. #9. There remained concerns of course, but everyone was looking forward to finally making progress on what now had been confirmed was actually causing all of Greg's pain and swelling. Greg also agreed that it would best for him to move into our home where we could be the most supportive of his time both in the short term and once he was undergoing the expected chemotherapy treatment.

Greg also checked messages on his cell phone and remarkably, there was one from Dr. #3's office indicating that he now had an opening for Greg to come to his office following Dr. #1's referral of Greg to him 93 days earlier. The suggested appointment was the same day as Greg expected to be in surgery and much too late to be of any use. Greg did not respond. To us, it was curious that he finally now had an opening coincident with action being taken elsewhere. (We hope to someday learn more about this. See lesson #1)

Day 403c-95a

Greg returned to his office at work hoping to talk directly to the people he worked with in order to bring them into the picture and to explain that he would be undergoing treatment that would reduce his ability to come to work full time. Greg also finalized an email that he had been working on the night before and sent it out to all of his relatives and his friends, explaining his situation and why he had not been more forthcoming before this.

Here is what Greg wrote:

> *I wish had better news to be contacting everyone with this morning but wanted to give everyone an update at once.*
>
> *Yesterday I was diagnosed with testicular cancer, or at least a 99% probability of. I have*

been experiencing some symptoms for a number of months, mainly lower back and abdominal pain, and the over the last few weeks the diagnosis has lead to testicular cancer, that was confirmed yesterday. The abdominal and back pain is a result of a relatively large mass present in the back of my abdomen.

I am scheduled in for primary surgery to remove one testical at Rockyview General on Wednesday. It is planned for just day surgery with the possibility of one overnight. Tissue samples will be taken and sent to the lab to determine the specific type of cancer cells, these pathology results will take about a week. This will give final confirmation of the diagnosis and guide the next treatment steps. The most likely treatment will be several rounds of chemotherapy, and/or the possibility of further surgery. I am sure this is a little overwhelming and a shock to everyone but I chose to not talk much about it until I knew for sure. Testicular cancer is one of the most treatable cancers with an extremely high cure rate. I am confident I can come out of this in several months stronger than ever.

As a final note, I want all of you to know, that while I haven't been that forthcoming about my challenges and diagnosis up to this point, don't think that each of you hasn't been supporting me. I am blessed to have the most incredible family and friends, and it is through this group of shared experiences, memories and futures that I gather considerable strength. Christmas dinners, random roadtrips, bad jokes, late night movies, unexpected overnighters, acting like kids and playing with the kids all make it easy to get up in the morning and look at this challenge as merely a bump in the road to be overcome and no more. Each of you gives me more strength than I will ever be able to describe and for that I have all of you to thank.

All the best and see you soon,

Greg

Later that day, Greg took a call indicating that his surgery was scheduled to be at 8:30 in the morning the next day and to be at the hospital at 6:30 for the admission procedures.