

**ONLINE ACCESS TO HEALTH INFORMATION**  
**Issues of inclusion for disabled and other patient groups**

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**Personal Advocacy for Comprehensive Health Access System:  
Disabled Patients' Perspective**

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**Intro:**

Access to health information, *especially when a control group of individuals brings with them a specific set of evolving symptoms and unique physiological deformities*, is a particularly attractive proposition for the patient and his or her GP /caregiver.

As a thalidomider now approaching his middle forties, I come before you with the succinct purpose of conveying just how (at best) inconvenient and (at worst) vulnerable and susceptible we are to misdiagnosis and poor medical treatment when well intentioned and highly capable health care professionals have no access to patient information or history. For the better part of my life it has been a repeated case of me "educating" the health care provider first to the history of Thalidomide, its patterns of deformity and then finally to the specific condition that has brought me in for care. In emergency cases, as I'll share with you briefly, time lost while A&E staff tried to "locate" a vein to administer medication worsened an already critical situation and literally brought me within minutes of possibly losing my life.

To best underline my advocacy for online access to health information I'd like to very briefly share with you three anecdotes from my own checkered past. I am certain that each Thalidomider possesses similar experiences of communication breakdown and self diagnosis. The wider situation is no doubt more tragic and comical than is summed up in my experiences to date. All the reason we should move ***with a degree of measured haste*** to begin implementation.

**Situation 1:**

As a 16 year old, while taking my dog for a run, he ran ahead and leapt in front of my feet while in full stride. In an attempt not to crush him, I lost rhythm and tripped over him landing squarely on my right shoulder - severely dislocating it. In the Emergency Room – there was an environment of panic as orderlies tried to understand the unique structure of my shoulder. Even with an X-ray they were at a bit of a loss. I found myself with two individuals pulling and twisting my right arm with my body weighted by bags of (lord knows what) and at least four other individuals stabilizing me and pulling in a contrary

direction until eventually success. I remember distinctly the relief as they *happened* to get it right. **Not one member of the team had any real idea how to address the alien nature of my physical form.**

### **Situation 2:**

As a very active 17 year old student and athlete, I found myself having developed pneumonic blebs on my lungs while on an experiential learning and teaching ocean adventure. After three weeks on the Atlantic aboard Gen. George Patton's schooner the "When and If", I found myself back on land with gradually increasing difficulty breathing. By week's end, barely able to draw breath and suffering from pronounced pain in the rest position, I was rushed to the emergency room. I remember distinctly that the on duty intern was particularly terrified with what had landed as his responsibility – on his shift - in the absence of the chief A&E physician. He literally had to contact that physician on the phone and be "talked through" the procedure – all the while trying to describe my physical deformity and discern how exactly he was to proceed. **In short, he botched it.** The tube to re-inflate my left lung was painfully inserted incorrectly. I am not a GP and will not pretend to understand what happened next but somehow after a second equally painful but successful effort, the muscle / tissue damage from his first effort, left the area around my left scapula wrapping around to my left chest numb for the next 12 to 15 years.

### **Situation 3:**

In January 1994 while in Toronto, Ontario, I had an allergic episode to an unknown agent. Never having a history of particular allergies, I waited too long to seek medical treatment. By the time I arrived at A&E I was very much in advanced anaphylactic shock. My veins had begun to collapse making it nearly impossible to locate them much less apply an Intro-venous line. Granted, this made a critical situation worse, but over the years **it was very common** for me to have to wait as various nurses struggled to locate a vein on my right arm. It was always that slightly frightened apprehensive look as they pondered, sometimes out loud, as to how exactly to proceed.

### **Concerns:**

Strategy:

- During last fall's ***Direct Electronic Patient Data Entry workshop***, I encouraged the assembled professionals to "***re-visit the notion of what constitutes "disability" \*as any condition or affliction that interrupts the ability of the individual patient to fully implement necessary life objectives.***
- This extrapolation of what qualifies as "disabled" to a wider social circle provides **an extended overarching justification for remote access** (where mobility or "normal communication issues" exist) and **feeds nicely into a larger, more comprehensive assessment of problems**

**regarding patient access.** \*Whereas a standard keyboard can provide for the needs of a fair percentage, it would be the same hindrance to thalidomiders with faux-chamelic limbs as those with for example - advanced arthritis.

- A comprehensive online health information network **clearly** will provide GP's with a **critical advantage** for quick assessment and appropriate directed care management.
- We are at a **"Time Intersection"** between clinicians' needs, evolving clinical practices, the control group of patients' needs ...and technology. A structure for **"Information Access"**, \*as we need to utilize it, is already in place with the internet. Issues like security can be addressed by current proven protocol. There's also the possibility that through the engagement of the thalidomide and other control groups, existing technology (like chip & pin) could be re-directed for use in an A&E situation. Consider a patient card with embedded codes that could be handed over to the attending physician. Such a device could unlock not only the personal records of the patient but immediately link to the larger Thalidomide database or more particularly a database of X-rays and case histories of other Thalidomiders (for comparative analysis).
- **Such databases could list common** but contextual "at-a-glance" information such as:
  1. **The most common medicines used by the control group over the test period.**
  2. **The most common practices utilized for pain management.**
  3. **A database (bulletin board of patient web logs or "blogs")**
  4. **A Research link to wider issues of manufacturing and continued use and distribution of the drug.**
  5. **A stock of patient X-rays with other clinical and detailed photographs of varied forms of disability,**
  6. **Recently published papers etc.**
  7. On the whole, the positive here is that such a network would be **rather easily translatable to other "control groups"...**name your "disability."

### Summary:

What some see as political correctness - (a continuing catalog of social concessions for the disabled), we the disabled see as vital steps to ensure our basic rights and dignity in everyday and emergency situations. In particular, as a Thalidomider I am one of a select group who inhabits bodies that for the most part **remain alien vessels to those with only peripheral exposure to the drug's legacy.** We Thalidomiders are not special in this fact. Those also disabled by other pathologies and neuro-muscular diseases face the same situation of having to spend valuable time "educating" our professionals to the individual but basic history and complexity of our physical selves.

We the disabled live on the frontline of healthcare. The prescription for dealing

with our healthcare issues is being written daily, hourly as we age and patterns and commonalities evolve. Serious ***consideration must be given*** and ***practical emphasis must be put*** on those who can \*convert our practical needs into a new healthcare reality. There will indeed be a trickle down effect Lessons learned from a pilot program of secure assistive technologies as part of larger interactive online health information network will make the case for its integration into a more efficient and patient effective National Health Service.

Thank You.