

ALEX'S STORY

May 1993 – Alex born a normal, healthy boy.



1996 – grommets put into ears following hearing problems. Difficulties with toilet training.

1997/98 – continued difficulties with bedwetting and continence at school. Improved throughout the year. Referral to child psychologist with no result. GP reluctant to pursue further. Social and educational skills progressing well.



1999 – good progress at school, socially popular, develops a liking for sport especially football and ju jitsu.

February 2000 – birth of brother. Alex extremely happy.

July 2000 – teacher reports inattentive in class on occasion. Otherwise no worries at school.



Summer holidays 2000 – uncharacteristically naughty behaviour and fighting with friends.

September 2000 – new class teacher concerned about Alex's hearing.

October 2000 – hearing test at hospital – comes back normal. School still worried as Alex obviously not comprehending what he has heard. Squinting at books. Handwriting getting very bad. Eyesight test – again normal results.

November/December 2000 – referred to community paediatrician. Does several tests. Verdict – needs urgent referral to a neurologist. Meanwhile Alex is constantly getting lost in school, needs assistance to find toilet, cannot be left in playground alone, walking into things, losing things that are right in front of him.

December 2000 – sees paediatric neurologist at Kings College Hospital. Instant referral to Guys Hospital for neurological tests after Christmas.

15 January 2001 – after a happy Christmas go to Guys for tests. By now Alex cannot walk without an adult on each side of him. EEG normal, it's not epilepsy.

16 January 2001 – MRI scan comes back with adrenoleukodystrophy. Told to go home, give Alex anything he wants and wait for the inevitable.

19 January 2001 – Alex says he feels slightly unwell and then has a massive fit at home. Ambulance called and Alex taken to resus as not making proper respiratory effort.

22 January 2001 – after three days in intensive care Alex wakes up to say he can't see.

25 January 2001 – told need to have Alex's brother, Ayden tested for adrenoleukodystrophy as it is a genetic disorder. Both boys have tests for adrenal failure. Alex is put on replacement steroids as test comes back positive. Ayden's test is negative at this point.



28 January 2001 – return home and start making plans for future.

February/March 2001 – mobility getting worse. Attending school for a couple of hours twice a week with special assistance. School finding it hard. Alex extremely clingy. Can no longer write and finds it difficult to feed himself. Alex given splints to help his mobility and to keep his feet in the right position. Wearing them at night starts to give him pain. Alex starts to attend a hospice day centre – hates it. We are told to persist.

April 2001 – decided Alex can no longer come to school as having difficulty managing stairs. Take boys to Disneyworld, Florida for dream holiday. Alex is still mobile, just, but take a wheelchair. Alex in wheelchair for most of holiday. Speech starting to slur and eating becoming more and more difficult. Wearing nappy at night. Still hates day centre. Ayden diagnosed with adrenoleukodystrophy.



May 2001 – wheelchair bound now. Posture bad and slumps all the time. Speech near incomprehensible. Needs to be fed now. One leg and arm getting difficult to bend. Fully incontinent now. Still hates day centre.

June 2001 – major concerns about amount Alex eating and drinking. Losing a lot of weight. Gastrostomy done mid June. Cannot understand Alex at all now. Persistence with day centre starts to pay off – Alex will stay there on his own now without crying. Alex tries to communicate by tapping hand once for yes and twice for no.

July to September 2001 – moved to more suitable disabled accommodation. Alex extremely uncomfortable constantly. Muscles constantly tense despite medication. Horrific problems with wind. We start trialling medication and dosage. Various strategies are tried to help symptoms. This goes on for over two years. On the good side Alex starts having laughing fits that last for sometimes hours.

September 2001 – Alex starts special school. Great relief. Can no longer use hand to communicate.

October 2001 – contracts pneumonia from chest infection. Three weeks in hospital followed by first respite.

November 2001 – major changes in routine to accommodate prevention of further infections. Chest physio and suction done daily to prevent further chest infection, urine tests done weekly, all feeding equipment sterilised, nobody allowed near us when ill. School having problems coping but persevere. Ayden put on replacement steroids as routine test detects adrenal failure.

December 2001 – Alex’s spine starting to curve so chest brace fitted. Also helps prevent chest infection and seems to be helping with wind.

January to April 2001 – Alex’s laughing fits diminish.

May 2001 – Alex stops smiling.

June 2001 to December 2002 – constant problems with muscle spasm, wind and infections. Care packages not working. Huge problems with positioning.

December 2002 – finally get social services to provide registered nursing care for Alex. Big improvement. Finally get referral to Homeopathic Hospital. Alex starts homeopathic remedies for wind.



January 2003 - Admitted to Guys for muscle tone review. Told knee joints fused and will never bend again.

January to June 2003 – homeopathic remedies starting to work well and wind problems greatly reduced. Start to reduce pharmacological medication for wind and bowel problems. Big improvements. Only drawback is no more sounds from Alex – he is too silent.

July to December 2003 – homeopathic doctor starts working on Alex’s muscle tone and remedies again are working. Alex more relaxed and flexible. Winter brings another problem in keeping hands and feet warm. Alex smiles on Christmas Day.



January to June 2004 – Start alternative therapy with Hrach Ogali <http://www.mindinstructor.com>. Alex can now bend his knees to 90 degrees, is beginning to gain control of his limbs and is making small sounds again. Gradually wean him off muscle relaxants, baclofen and clonidine. Weaning successful with no adverse results.

July to September 2004 – Alex making good progress. Can now eat a whole pot of fromage frais or equivalent soft food in one sitting and making more and more noises. Is obviously trying very hard to communicate on occasions.

September 2004 to April 2005 – Alex now eating same food as rest of family – food is blended and portions small, but within a few weeks is eating well enough to come off tube feeds completely. Also drinking thickened drinks, quantity increasing over the weeks. Tube only now used for extra water and medicines. Alex moves to secondary school in September 2004. Agreed with education authority that he can go in part time spending two weekdays at home to concentrate on Hrach Ogali’s therapy. A charity buys Alex a specialised bicycle that he can cycle from his wheelchair and he starts to use this regularly. The cycle can be run on a motor to exercise the legs or taken off the motor so Alex has to cycle himself – he can do this for sustained periods of up to two hours on first gear. He can also do second gear for

up to 30 minutes at a time. Alex is weaned off carbamezapine with consultant neurologist's consent. This is successful and there are no problems with this. Some very minor fits are observed from time to time but Alex snaps out of these very quickly.

April 2005 – Alex comes home from school with a broken femur and is in traction for six weeks. Investigations are ongoing to date. Leg heals very well but is an obvious setback in physical rehabilitation. Decision made that education will now be done at home.

June 2005 to February 2006 – Alex begins to receive Hratch Ogali therapy at home with trained individual for eight hours per week. Blinking responses for yes and no are seen to improve. He is able to move his left toes on demand and begins to exhibit similar movements with other limbs. Sounds increase in volume and amount. Actively resists certain activities such as changing. Will not eat certain foods consistently which have now been noted as disliked and he blinks to confirm this. Eating has continued to improve and weight is stable. He can now eat food with soft lumps and has begun to bite and chew foods such as banana. Can eat Skips crisps and chocolate buttons. Drinking has also improved and now has up to four oral drinks of 200mls per day. Tube feeds still not needed and only 800 mls water per day and medicines administered through gastrostomy. Decision to educate at home not supported or funded by education authority – this is being appealed to date. Link fostered with a local mainstream school for Alex's social integration and he is now being befriended by four boys a little older than him and attending sports functions, drama and music rehearsals, and debating society. Using bicycle again but can only do first gear.

May 2006 – Alex turns 13 and begins to shave (fortnightly!!).

September 2006 – Win appeal with education for home tuition. Home tutor begins October for 10 hours per week. Waiting for formal link with mainstream school so Alex can attend a lesson a week.

October 2006 to January 2007 – Improvements still noted with Hratch Ogali therapy. Alex's noises have become deeper and he is behaving in a very adolescent manner. Clearly stroppy and uncooperative at times especially when being changed and during physio. Can relax muscles himself when asked. Noted he is no longer being incontinent when not wearing a nappy. He is also making lots of noises when requiring a change. Particularly noted at night time. Movements more consistent now, in particular movements of arms improved profoundly. Turning head towards people speaking to him well. Blinking responses extremely good, particularly noted as strangers can understand them. In November at routine endocrinology appointment we request, on recommendation from Hratch Ogali, that Alex lower his dose of hydrocortisone to see if adrenal gland is functioning. Endocrinologist agrees (surprisingly!) and also writes letter to endorse mind therapy treatment. In March Alex will undergo a test to see if there is any activity in his adrenal gland – we are very excited about this. In December Alex manages to do second gear on his exercise bicycle for first time since he broke his leg. He continues to be able to do this consistently for prolonged periods. We continue to hope....