

Early Updates on Charlie – March 26, 2011, to June 15, 2012

Videos (If link does not respond, copy and paste to your browser):

Drums & tambourines: <https://www.youtube.com/embed/XaI9ukugSAI>

Toys at Hospital: <https://www.youtube.com/embed/InpRWad6POI?rel=0>

Baptism – Esther & Charlie: https://www.youtube.com/embed/S3c-vXwEW_c?rel=0

Hospital kiss: <https://www.youtube.com/embed/sS4HBlaT7as>

Sleeping with Mummy: <https://www.youtube.com/embed/LR-d2pjn0Kc>

The Pianist: <https://www.youtube.com/embed/dHw-fV4XJ1U?hl=en&fs=1>



Updates

March 26, 2011 - Following problems with vision which could be symptomatic of a brain mass, Charlie has a CAT scan. The scan is reported to show no evidence of a tumour.



April 1, 2011 – An MRI reveals a brain stem tumour - "*diffuse intrinsic pontine glioma*".

April 2 - Heavy steroid treatment begins with "decadron". Side effects include obsessive-compulsive behaviour, aggression, sleeplessness.

April 3. Charlie gets upset with having to take medication, rips out his IV tube! Seems calmer by the end of the day and begins to interact with people other than mummy and daddy.

April 6 - Radiation therapy begins. He will have this every morning, Monday to Friday, for 6 weeks.

April 8 - Charlie comes home from the hospital - hurray!

April 10 - Charlie and his big sister, Esther, are baptised at the People's Church in East Lansing. They are surrounded by parents, grandparents, one aunt and many great friends. It is a joyous occasion despite the tragic circumstances, and a beautiful way of showing such a strong community of affection for Charlie and his family.



April 15 - Charlie completes his first week of radiation. Although there have been good days and bad days, he is doing well and his spirits are high.

April 18 - Radiation therapy resumes today. Charlie has had a good weekend. His high spirits returned on Sunday but nights have been difficult with the parents getting little sleep.

April 21 - Nearing the end of another week of treatment, Charlie's has been quieter today after his radiation this morning, but in good spirits. As we were all warned, his appearance is changing as a result of the steroids, becoming more like his round-faced namesake in the "Peanuts" cartoon -- but the smile is the same old Charlie!

April 24 - Easter. The family went to the People's Church here in East Lansing. Charlie happily slept through most of the service. Talking of sleep, Abby, John and Charlie are getting a little more now. Charlie's Decadron dosage has been reduced to two 1 mg. doses every 24 hours which means not having to wake him up more than once during the night -- and one side effect of Decadron is insomnia. But codeine helps.

April 26 - Second day of the third week of radiation. In the day time Charlie is reasonably happy, playing with his animals. His change of appearance from the Decadron is even more marked. Nights are not so good -- pain or hunger pangs wake him.

April 27 - Charlie slept better last night, though John and Abby kept waking up, unable to shake off their long conditioning from other sleepless nights. Today his natural merriment was more apparent, hi-fiving his grandparents and giggling when engaging in a mock fist fight. His jolly moods are interspersed with grumpy ones that are almost certainly a side effect of the steroids.

May 3 - Another rough night, but Charlie's mood is surprisingly good considering the misery of the side effects of Decadron, the steroid he has to take to reduce brain swelling. Adult patients, perhaps, are able verbalise these side effects more clearly than Charlie, and so comments posted about the drug on askapatient.com are helpful in understanding what he experiences.

May 9 - Radiation therapy has become increasingly difficult over the last two weeks. Charlie is sedated for radiation and, in order to keep him in the same position so the beams hit their targets, he has a specially fitted mask which looks a little like a fencing mask. Bolted down, it keeps his head immobile. The swelling of his face due to the steroids makes it hard for him to breathe once his mask has been fitted, though the medical staff do a fine job in making him safe. After radiation today, Charlie was wheeled to the lab for the first MRI scan since his treatment. We will find out tomorrow whether the tumor has been shrunk, stabilized or untouched by radiation.

May 10 - Late this evening, after an anxious wait, Abby and John heard that the results of Charlie's MRI are promising. The tumour has shrunk modestly and has not spread further. This gives reasonable hope that he will have some months post-radiation of relative normalcy. Tomorrow morning they will learn more and discuss how much additional radiation, if any, he will receive. Charlie had a fairly good day, though it is proving ever harder to find foods he wishes to eat in spite of a voracious, steroid-induced, appetite! Dill pickles remain a firm favourite.

May 11 - John and Abby met with the radiologist this morning who confirmed that Charlie has responded well to radiotherapy. The radiologist was certainly not expecting so much shrinkage and had considered it perfectly likely that the tumour would have continued growing. So good news. Of course, there are no guarantees that this will give Charlie a long period of respite, but at least the probability of a very rapid decline has been reduced. He had another dose of radiation today and will have his final one on Friday. His steroid dose has been reduced and he is currently recovering from sedation, eating a large cinnamon bun before tucking into a series of bags of cookies, pasta and swiss rolls.

May 12 - Charlie had a good day yesterday and went into radiation this morning far more relaxed than in previous weeks. It helps that the nursing staff in the outpatient ward and in the radiation department are wonderfully compassionate. One of Charlie's nurses spent time helping set up the fundraiser sale yesterday and his radiation nurses today gave him a giant cuddly frog (one of many gifts received from them). Fellow patients receiving radiation have also been remarkably kind. One patient today made a generous donation to Charlie's fund. Another asked for their red rose, given on the last day of radiation, to be passed on to Abby.

May 14 - Since it would have meant exposure to too many people, Charlie was unable to attend the hugely successful sale at the People's Church, even though he finished his radiation treatment on Friday. At the moment his condition remains unchanged but should improve as the Decadron reduces.

May 17 - Charlie has completed radiation and his steroid dose has dropped once more. His mood is volatile and he is still hungry much of the time, but he is also considerably happier than before and delightfully affectionate. Today he had a physical therapy appointment so that his parents could get some tips on restoring his mobility after weeks of radiation-induced muscle weakening. He is already

walking more confidently, though his thigh muscles have degenerated so much that he tends to lock out his knees like a toddler. In time this should improve dramatically. It was also good to see Charlie play with another child today without the wariness of recent weeks.

May 19 - Charlie had an excellent day today. His mood and his mobility are so much improved on even just a few days ago. This is presumably a result of no longer having to go in for radiation and a reduction in his daily Decadron dose. Each day Charlie is more sociable and plays with increasing enthusiasm with grandparents and visitors. Charlie's physicians and his parents continue to search the literature for effective chemotherapies. As expected, there is little sign of new treatments emerging from current clinical trials. For the present, however, it is a delight to have Charlie back again.

May 20 - Charlie had another good day today. Each day he brightens a little more. Over the past week he has played more and more comfortably with his grandparents and is responding well to the arrival of friends and favoured dogs. Today he also spent some hours outside and attended a bake sale at Esther's school. This is very encouraging. His appetite remains something of a problem: four courses before 4am is not unusual but leaves his parents fried. Then again, there is definite pleasure in seeing him grin through five large slices of pizza. Charlie has also become more affectionate as he begins to feel better.

May 22 - A mediocre weekend for Charlie. His mood was flatter than in the previous few days and he was quicker to cry and show signs of anxiety. One of the basic difficulties is that Charlie still has a language delay and so cannot always communicate what he is feeling and experiencing. On both Saturday and Sunday Charlie withdrew somewhat, though we do not know why. This kind of volatility is to be expected on Decadron, though it also seems likely that the steroid is magnifying the trauma of so many weeks of hospital visits which he could not comprehend.

May 23 - Esther's birthday. (A generally better day for Charlie, in spite of having to go to the clinic to have blood drawn (his immune system is in pretty good shape). Charlie went to dinner with his grandparents and tolerated the experience very well. He drove his Dad half-mad with his continuous demands for food and his almost-certain refusal of anything offered (!), but was once more quick to laugh. Charlie's body weight has increased by nearly a third over the past month. With a further reduction in his steroid dose today, we are expecting his mood to become more even, his sleep more regular, and his hunger pangs to slowly recede.

May 24 - This morning Charlie seemed to take up where he left off later last week. He is happier, more interactive and a little less liable to explode into rages.

May 26 - Charlie's week has been as good as we could have hoped for. We have constantly worried about whether his rages, wariness about seeing people, and obsessive behaviours are due to the trauma of so many hospital visits or to his steroids. This week his dose was once again reduced and while his appetite remains high his mood has improved noticeably. This gives us hope that his old personality will have time to reassert itself – that his emotional hardships are mostly steroid-induced. Over the last three days Charlie has enthusiastically left the house to play with others, including this evening the small children at the birthday party of Esther and her best friend Sylvia. In spite of all the happy chaos of the

party, Charlie was cheerful, relaxed and clearly pleased to be there -- the best evening in two months. By far.

May 30 - The improvements in Charlie's mood and mobility have been astonishing over the past week or so. In some ways this is even more heartbreaking because we know that every gain will eventually be lost. Happy moments are tinged with sad reflections.

As some degree of normalcy returns, our minds are free to contemplate the future and we become aware that our lives are from how on far from normality life. Persistent lack of sleep magnifies such painful thoughts, and yet it is still remarkably easy to focus on the present. We enjoy each occasion on which Charlie laughs or smiles, and we see fulfillment in the present as utterly worthwhile irrespective of what the future inevitably holds.

One other thing, Esther is an absolute angel with Charlie – she only has a vague awareness of what is happening, but she is showing herself to be a very kind and creatively caring child.

June 4 - Much more participative and alert today, Charlie spent the morning at Potter Park zoo in Lansing -- probably his favourite place of all.



At a friend's house that afternoon, Charlie played in the pool, a joyful, laughing toddler again. Later he went to sleep faster and happier than at any time in the last two months.

June 5 - Charlie's back. There's a little more of him than before, and some of his obsessive behaviour still remains, but his personality has largely reasserted itself. His amusing blend of affection and boyish aggression has returned. Yesterday Charlie went to the zoo, withstood a brief TV appearance yesterday as part of a local fundraiser, and spent the evening with friends. Today he went with dad and sister Esther to a local leisure centre with a fabulous outdoor pool. When he realised where he was going Charlie began to chant 'pool, pool ...' with mounting excitement. We went back this evening and Charlie played with one of his closest friends, Cameron, with an ease and enthusiasm we haven't see for nearly three months. It's very gratifying. Long may it last.

June 8 - Another very good day. Charlie accompanied Abby shopping, played happily with his speech and language therapists, attended a performance at Esther's school, and spent hours splashing in a paddling pool. Best of all, during the evening he played continuously with an older friend, 'JD', without requiring any comforting from his parents. That's a great stride forward. Tomorrow he has an MRI. Hopefully he will then be free from medical interventions for some weeks

June 9- Charlie was understandably aggrieved to find himself bound to the hospital this morning and even more upset to be poked by a needle and sedated for his MRI. But he came round fast and spent a wonderful evening playing with his English grandmother who arrived today. This is really the beginning of the 'honeymoon period'. We have spent some time exploring possible chemotherapies with our oncologists. Absolutely nothing works for DIPGs. In fact, some years ago – we learned today – British researchers stopped looking for cures. The research gave rise to side-effects and false hopes without in any way harming the tumour. One of the few channels left to consider is a highly controlled diet which seeks to deprive tumours of nutrition; there is at least some work with mice which suggests this might become a new direction of treatment. We'll go on researching it over the next few days. Given the dismal track record of attempts to treat DIPG, it is unwise to get ones hopes up or to risk jeopardising quality of life in the child's final months.

June 17 - Charlie is a happy kid again. The only apparent effects of his treatments are his chubbiness, caused by the steroids, and his refusal to eat nearly all the food he is offered, presumably caused by his coming off steroids. In all other respects he is how he used to be. Over the last week he spent three days with his parents, sister and grandmother in the beautiful countryside of northern Michigan and returned to have a splendid birthday at the zoo. His obsession with all things dinosaur continues undiminished. Since he insists on having these with him most of the time, it now takes two people to carry his three crates of plastic dinosaurs up and down the stairs. Sooner or later we will have to start thinking about not always letting him have what he wants – he will, after all, become a normal child again with typical urges to test and cross boundaries. But not just yet.

For more, see: http://www.statenews.com/index.php/article/2011/06/a_day_to_remember/

June 15 to June 22 - See TV update:

<https://www.facebook.com/pages/WLNS-Ann-Emmerich/122407057843473?sk=wall#!/video/video.php?v=2089853001998&oid=122407057843473&comments/>

June 22- Charlie attends the "Art for Charlie" Art Show. It was a late evening and after sampling hor d'oeuvres and wrestling with attendees for the first part of the show, he later settled in a corner of the dining room, soon to be fast asleep:



July 10 to July 17 - Charlie, his sister and their parents are in San Diego on a trip arranged by the Make-a-Wish foundation for Charlie to see the San Diego zoo. First reports suggest it is a huge success with visits to the wild animal park and a ride in a balloon.

July 22 - Charlie's cousins Inigo and Oriana with their parents, Darian and Alison Stibbe, come over from England for a two week visit. Charlie takes them to Lansing's Potter Park zoo, a favorite place that rivals San Diego. Picture left to right are Inigo, Charlie, Oriana and Esther.



A weekend treat for the for the two families will be a trip north, leaving July 27, to spend a few days on Beaver Island, the former kingdom in the middle of Lake Michigan.

On August 1. Charlie returns to Sparrow Hospital to start an experimental program on the ketogenic diet.

August 4 - Back home from hospital. After a glorious few days on Beaver Island, Charlie had to go back to Sparrow Hospital on August 1 to start his ketogenic diet through a nasal drip. It's a tough routine but Charlie is handling it well and has shown himself to be metabolically adaptable to ketone nourishment. A promising start.

August 22 -- More of Charlie's cousins, Nika, Tanya and Maya, arrive from England. This time it is the family of Abigail's brother Adam. With the routine of the ketogenic diet, trips to the lakes are not practicable but the family has fun enough in East Lansing.

August 25 - Back to hospital again! Charlie has a fever of 102° and needs to be monitored. It proves a normal toddler virus, but, in requiring blood tests and two days of monitoring, it is a reminder of the ever present risks in Charlie's now near normal life.

September 3 - Adam and family leave for England. It has been a companionable time for the cousins, albeit with two days spent visiting Charlie in hospital. Charlie and his two-year old cousin Maya found much to laugh about together.



September 19 - Today Charlie went in for an MRI. Abby has begun to see signs consistent with possible progression of the tumor. Charlie's tantrums have acquired some of the intensity of the weeks before his first MRI, when cranial pressure was building up.

One of his eyelids is failing to close completely at night. Both symptoms may, we suppose (but certainty is elusive!), be related to the ketogenic diet. Either way, in the next 24 hours we ought to know if the tumour is growing. Charlie was distressed going in to the hospital today and having his port 'accessed', though he came round from anaesthesia well and was tearing into some KFC (he is on a high fat diet!) with happy vigour within an hour.

I (Dad) came home later today to find two very happy kids rolling around on the floor with their mother—and cold, congealed KFC. Mmm. (Actually, that's not quite fair, a friend had also delivered some of the nicest samosas we've ever eaten). KFC isn't really very ketogenic—too much carbohydrate in the batter. A week ago, Charlie's appetite began to climb and climb. Again, it's anyone's guess why—typically the diet reduces hunger pangs because fat kicks around in the stomach sending 'I'm still full' signals for rather longer than protein or carbs. But as a result, we could not satisfy his hunger by only giving him a few grams of protein and carbs a day.

So, we have relaxed the diet, and – for the first time in six weeks – do not weigh everything he consumes to ensure that it conforms to the 4:1 ratio [the ratio of fat to total combined carbohydrate and protein]. Charlie has been thrilled to eat something approximating what the rest of us consume.

Esther, who feels Charlie's misery at less than appetizing meals just as keenly as we do, announced a few days ago, "Please can we not put Charlie back on the proper diet – what's the point in living if you're not having any fun?"

So, if the MRI comes back with any degree of shrinkage or just stability, we'll ease Charlie back into some degree of ketosis, though perhaps not as deep as before. But Esther makes a fair point (she's a smart little owl). While there's supportive data from mice, it's not strong enough to justify the diet if Charlie perceives it as a kind of torture. We'll do our best, but explaining the need for it to a three year old is profoundly challenging.

Since this is my first update for a long time, I should point out that Charlie has over all had a splendid summer, courtesy of a beautiful and loving personality, a very fine extended family, and wonderful local friends, big and small. He's even picked up some bad language!

September 21 - There's devil in the detail: the MRI report, received today, states that the tumour looks stable. But the radiologist saw some changes to its appearance and, depressingly, an increase in fluid retention in the brain's ventricles.

Although we are not really in a position to interpret the report, it is hard to believe that anything could cause the fluid build-up except for progression since it is the tumour which blocks the drainage of water from the brain. Moreover, observations of a child's behaviour are often said to be a more accurate means of identifying early stage DIPG progression, and Abby noticed about three weeks ago that Charlie's right eyelid is not closing entirely during sleep and his tantrums have become prolonged and intense. These were two of the symptoms which led Abby to request an MRI back in March (it really is remarkable to see Abby's unflinching courage in continually checking for signs of progression in spite of her desperate desire to find none). We hope to hear more definitively from a very fine NIH researcher in the next few days about whether progression is underway.

At the moment, however, it does not look good. And we need to know soon what is happening because we have to decide whether to enroll Charlie on a new protocol at St. Jude's in Tennessee, start him on palliative drugs, and begin to prepare ourselves and Esther for what is to come.

On the positive side, he is currently roaring with laughter in the bath with a sister who is very skilled at both amusing and annoying him!



October 19 - About a month ago we feared the worst - that progression of the tumour was once more underway. About two weeks ago another clinician, who is an expert on DIPG, read the MRI and was far less certain. Late last week a third DIPG researcher got back to us with her view that the tumour is indeed stable.

We're obviously deeply relieved. Charlie's burst of tantrums and his eyelid failing to close fully are hard to explain, as is the recent improvement in both respects. Then again, the acid reflux which blighted his first couple of years has now returned, and once again we are left confronting the utter mysteriousness of this tumour. For the present, however, we are carrying on as normal, assuming that the tumour is still quiet.

Charlie seems to get more adorable all the time. He has thrown himself into the many opportunities which preparing for Halloween brings, like roaring and pretending to be a dinosaur.

November 13 - On Sunday, November 13, the family left for Washington for Charlie to attend the NIH (National Institutes of Health, in Bethesda, Maryland. After continuing uncertainty and some false alarms regarding the progression of the tumor, John and Abigail applied for Charlie to participate in an advanced imaging study. On this first visit they will be there a week. More visits are likely to follow. While it is unlikely any cure will be found, the study will help to obtain a clearer prognosis and could well contribute to our overall knowledge of DIPG.

(From a photo just received while they were en route to Washington, Esther and Charlie have clearly been required to take over the controls -- airline staff shortages now becoming acute.)

November 14 - Charlie arrived in Washington in good spirits and, after being cleared for his MRI on Sunday, was refused today because of a cough and lung congestion. The family will meet with doctors tomorrow to decide whether to stay on a few days to reschedule another scan, which will incur some substantial expense, or come back another time.



November 15 - A good meeting with NIH staff doctors this morning. Since Charlie is not showing current signs of progression they will not reschedule the MRI for this visit -- particularly since his lung congestion may not be clear in time. Instead there will be another visit in January. Meanwhile Charlie has been accepted to the NIH protocol, which makes this trip worthwhile. Tomorrow the family will tour Washington and stay with cousin Jim Graham-Yooll and family.

December 14 - Advent and the approach of Christmas. Charlie, as excited as any three year old, helps Esther decorate Christmas cookies.



Christmas period to January 14 - There is pleasingly little to report. Charlie is as happy, active, loving and amusing as any 3 year old could be. Over the past few months there have been no indications that the tumor is returning. Unfortunately he could not have his MRI at the National Institutes of Health in November because of nasal congestion; then again, his mood and mobility indicated to his primary oncologist, Dr Kathy Warren, that he is doing fine.



The Night Before Christmas

Charlie was thrilled to have Santa come to his house early in December and Santa was apparently willing to forgive Charlie's irreverent blowing of raspberries, giggling and running away. Christmas morning was delightful, with a good crop of Charlie's favorite toys: rubber animals of any description. The family all travelled to Chicago in early January where another specialist, Dr Stewart Goldman, also became involved in Charlie's care. A very good team is now in place for when Charlie does begin to deteriorate. In two weeks he will have two long MRIs and PET scans as part of the NIH's research protocol. It is always possible that such scans will reveal tumor progression, but at present Charlie does look incredibly well and he is enjoying life with a wonderful intensity.

January 27 - We have just returned from the National Institutes of Health in Washington where Charlie had two long brain scans under the supervision of Dr. Kathy Warren. The big question, of course, is 'has progression begun?' Unfortunately we do not know. The overall size of Charlie's tumor remains the same as when it was scanned at the Sparrow Hospital, here in Lansing, in September. There were a couple of areas of the tumor which look different, and larger, than on the September scan. But there is no way of saying whether this is progression because the NIH scanner is at least double the intensity of the one here and so we might just be seeing components of the tumour which were there in September but not discernible on the scan. The analysis of the different nutrients in the tumour revealed some activity, though probably not enough to suggest that the tumor is growing back at a fast rate. All in all, then, there are several possibilities and we won't have a clear picture until Charlie's next MRI in March or if his walking, vision or swallowing decline or he begins to experience severe headaches. We are, at

least, in very good hands. As for Charlie, he was magnificent. In spite of two long scans he spent yesterday evening playing hard and fast with Vanessa, daughter of Jim and Susanne Graham-Yooll, who provided much needed warmth and wine after several days at the hospital.

March 23 - On Wednesday Charlie had a second MRI at the National Institutes of Health in Maryland, where he played a convincing doctor (see photo). To our great relief the tumour is the same size and has the same level of activity as it did in January. Presumably it has not grown at all since diagnosis and radiation in April and June of last year.



Charlie himself gets happier, fitter and more adorable each day. He wakes up with a smile, plays eagerly with his sister, enjoys his preschool, and has a beautiful temperament: lovingly affectionate and boisterous by turns. He is also very vocal (in fact he chatters away till the moment he falls asleep) and it has been a deep joy to watch his speaking blossom. Speaking of blossom, Charlie is thrilled by the reappearance of life after the winter. Insects, birds, flowers all delight him. Esther too is doing fine. She takes care of her brother with real gentleness and regularly reduces him to giggles. If sadness is a routine feature of his parents' lives, Charlie brings us much pleasure by experiencing so much of it himself.

April 7 - Charlie falls in love.

She's pretty, affectionate – and (well, fairly) obedient. Her name is Boston.



On Saturday morning during the Easter weekend, Boston, a six-year old Golden Retriever arrived to join the family. Trained as a service dog, but not quite making it, Boston made immediate friends with Charlie and Esther, and identified herself from the start as a gentle and very loving companion.

April 18 - Over the last few days Charlie has been more restless at night and, on a couple of occasions, has complained of pain, though he does not – or cannot – tell us where. We've been here before: both before diagnosis when his hydrocephaly was very bad, and again a few months ago when we wrongly supposed the tumor was returning. So we don't know what to make of his waking and will just wait to see if the problem goes away or worsens.

Several incidents like this over the past weeks have reminded us how urgently we need to live life so as to bring as much joy to Charlie as possible. To this end we are planning a road trip across to Oregon and into the Canadian Rockies for later this summer. It's hard for us to imagine a child who is easier to delight or is so rewarding in the affection and happiness he expresses. In some ways it also seems that the beautifulness of his daily interactions makes this experience harder and more painful.

"Cuddle me tight", he says when about to go to sleep, before adding, "Cuddle me more tight".

"I like everybody", he announces. After having said he likes someone, he is at once concerned that he has been too partial.

Charlie loves all things with a genuine intensity, coming quickly to the defense of mosquitoes and sobbing if a spider is killed. It gives a sharp edge to our knowledge of his prognosis that we are destined to lose a boundlessly kind boy who could only have grown into a good and loving man.

April 21 - An exciting day for Charlie, as the guest of the City of East Lansing.



Told about Charlie's story by the city's communications manager, Mikell Frey, George Lahanas, the newly appointed City Manager, immediately invited Charlie to bring his family and friends to spend an afternoon with the Fire Department, use a fire hose, and meet the Police Department's K9 dogs. Charlie and Esther with a dozen or so friends received goodie bags from the City -- and some special gifts for Charlie and Esther.

June 11 - Yesterday Charlie won an award from the Sparrow Hospital Foundation of Lansing as "*Cancer Survivor of the Year*" in consideration of his continuing exuberant love of life.

Last week Charlie travelled to the NIH in Maryland for his MRI. Once again, to our enormous relief, the tumour is stable. In fact the radiologist said it was identical to the previous two scans: the best result which, in the circumstances, we could have hoped for.

There is something odd about the reading. The scan also measures the levels of certain molecules in the tumour to see if one can predict progression by the changing ratios of different nutrients. One of them, choline, is a nutrient required for building new cell walls and so one would expect it to be high when progression is underway. Charlie's choline level is moderately high and yet it has been at the same level

for at least six months in spite of the tumour's stability. It would seem, then, that we can't read anything into this reading. It does emphasize, though, that the tumour is alive and well. But, for the time being, Charlie is a bundle of happiness and cheekiness.

He bounced back from the anaesthesia last Wednesday and spent all evening with his Graham-Yooll relatives in Maryland, playing excitedly with Vanessa, dogs and guinea pigs.

Charlie is four on Friday, a birthday which we did not think he would live to see and certainly not as the joyful, active and intensely loving boy that he is.

June 15 - 4 years old - a BIG birthday!

There was a party at the house with friends from school. They were all entertained by a reptile expert who brought live reptiles and insects and kept the young guests (and Charlie most of all) entranced for an hour -- watching and holding a variety of snakes and turtles.



Snakes?! Yes, snakes!

In Charlie's eyes, there may be "bad guys" (though, like pirates, they are not so bad when you get to know them), but there are *no* bad animals, reptiles or insects. The world to Charlie is good.