

Step by Step

ANNUAL REVIEW
2002



BIRD

Brain Injury Rehabilitation
& Development

www.b-i-r-d.org.uk

First Steps

Slowly but surely, BIRD's work is gaining the recognition it deserves.



Mr John D Smith, Chair of Trustees

Two years ago Elisha, pictured on the front cover of this publication, was unable to walk. Now, not only can she walk, but she can also communicate with her parents in ways they never thought possible.

You can read her full amazing story in this review of BIRD's work. For Elisha, what seemed an impossible dream just a short time ago, became a reality due, purely and simply, to the dedication of her family and of the BIRD staff.



Elisha's parents had been told that no further medical help could improve her life. The staff at BIRD proved, yet again, that this was not the case.

In many ways, Elisha personifies all that is good about the achievements BIRD has been able to make since its inception 20 years ago.

Like Elisha, BIRD is now taking its tentative first steps towards achieving greater recognition of its amazing work. For both Elisha and BIRD, progress comes after an immense amount of hard work, setbacks along the way and a sheer determination to succeed from everyone concerned.

I have never known any organisation that deserves support as much as BIRD. I hope you will find the BIRD story as compelling, miraculous and moving as I have since becoming Chair of Trustees in 2000.

I also hope you will join us in making sure that the many thousands of children and adults who could benefit enormously from BIRD's unique work - yet do not simply because they don't know of BIRD's existence - do so in the near future.

Please help us to bring renewed hope to those people, like Elisha, who have been told that there is no hope. I know that BIRD can make a real difference to their lives.

Mr John D Smith



*Dr David J. McGlown
Clinical Director and Chief Executive*

In the past year, we have been able to bring renewed hope and happiness to people who had given up that hope. That is why we exist.

Each year, during the past two decades, we have gradually been able to spread our message further afield, bringing our unique methods of treatment for children and adults with different kinds of brain injury to more and more people. Long may this continue.

This is a particularly poignant year for me as I am soon to retire from BIRD.

In so many ways, I am sad to be leaving this unsung organisation whose work has achieved more than most people will ever know. Yet at the same time, I am more optimistic about BIRD's future than ever before.

At times, it has been a struggle to meet the financial commitments necessary to maintain the very high standards of treatment we have set

"The best way to find yourself is to lose yourself in the service of others"
~ Mahatma Gandhi ~

Day by Day

Every day, people's lives are changing for the better with BIRD's help.

Don't believe in miracles - depend on them.
~ **Laurence J. Peter** ~

ourselves. We have managed this through financial prudence and the generosity of our supporters. Not a penny goes to waste. The only limitations on what we can achieve now are financial.

To this end, we are making greater efforts than at any time in our history to bring BIRD's message to a wider audience.

Our Community Outreach Programme, launched this year, aims to raise awareness of our unique treatment in urban and inner city areas. We hope to achieve this by 2005. We will also be informing a greater number of medical professionals about the benefits of our work and aim to raise far greater awareness of our work in political circles.

Our success in gaining sponsorship from the Community Fund to fund the position of Community Information Development Officer will enable us to offer information, advice and guidance to people wishing to learn more about our treatment services and how to access them. We will also be able to provide multi-lingual information leaflets to make sure everyone can understand what we do.

In February we launched our National Telephone Helpline which is proving to be an invaluable service.

Our website now has an on-line donation facility, to make it quicker and easier than ever before to provide much-needed money to support our work.

I am delighted to be able to announce that John Williams, our Fundraising Manager and Chief Executive designate will take up BIRD's reins formally in October 2003. I am confident that I am leaving this organisation in an extremely safe pair of hands.

I am equally pleased to be able to say that at the same time, Stephen McQue will become Clinical Director, continuing the clinical approaches we have pioneered and perfected over the past two decades. I extend my very best wishes to both of them.

Our methods of treatment make measurable improvements to the lives of those people we exist to help. In some cases, using the words of parents, those improvements are nothing short of 'Miraculous', a word not often used by Doctors.

In many cases, the families of our patients have been told by health care professionals that nothing more could be done to help. Clearly, these professionals have the best interests of their patients at heart when they give the families concerned this heartbreaking news. The sad truth, though, is that all too often, they are unaware of the effectiveness of the BIRD treatment.

You will read for yourself in this Annual Review, three of the examples of the quite remarkable progress we were able to make with two wonderful little girls - Olivia and Elisha and stroke victim Jim.



The experience of each of these people tells a remarkable story about the results we are able to achieve for people with brain injury of all types.

We can now do more than ever to enhance the lives of brain-injured children and adults.

I sincerely hope you will help us to do so.

Dr David J. McGlown

The BIRD Story

No-one else provides the type of treatment BIRD does.



BIRD is an independent charity providing treatment to improve the quality of life for people with brain injuries of all types, irrespective of age or severity.

Brain injury takes many forms. At BIRD, we aim to treat everyone who can benefit from our unique approach.

Most people with brain injury are born with the problem due to genetic reasons or complications during pregnancy and birth. Other people suffer trauma during their life from accidents, assaults and natural disorders such as strokes.

Consequently, we treat people with conditions such as cerebral palsy, communication disorders, dyslexia, dyspraxia (clumsy child syndrome) epilepsy, autism and children who are failing at school for no apparent reason. We also treat people who have had strokes or road traffic accidents etc. which have caused trauma to the brain.

Some of the children we care for are severely physically and / or mentally disadvantaged and may be blind with little or no head control. Others have mild learning difficulties, hyperactivity or behavioural disorders and are in mainstream education.

No-one else provides the type of treatment we do. Indeed, for most of the people we help, it was thought that no further improvement was possible, so no public funding has been made available. Yet we manage to markedly improve the lives of over 90 per cent of the people who come to us.

What makes our approach unique is our focus on the root cause of these various problems, namely injury to the brain, rather than the symptoms.

Around 85% of the people we treat are children and three-quarters of these children have severe learning difficulties.

Our therapists are specially trained in "Developmental Reflexive Rehabilitation" techniques. This means that they tackle the problems of reflexes in children and adults which have not developed properly from the infantile reflexes present in everyone in the first year or two of life.

Their professional skills cover neuro-psychology, physiotherapy, speech therapy, psychology, education, and the emotional disorders of children. By bringing their skills, experience and - above all - care, together at BIRD, they continually improve and refine our unique treatment methods.

Our Unique Approach

Before we provide any treatment, we always carry out a full neurological assessment. In this way, we can let a prospective patient's family know the level of improvement we hope to reach.

Our treatment involves two people who help the patient with his/her programme. These two people are usually family members, partners or close friends of the patient.

Patients and their carers are taught a specifically designed set of physical movements to practice. These take between 30 and 60

*In order to be irreplaceable one
must always be different.
~ Coco Chanel ~*

minutes each day and are not strenuous, so even the most physically disabled people can carry them out. The idea behind these movements is that they gradually feed information back to the brain to enable the patient to develop normal reflexes.

After the initial assessment and training programme for both the carers and the patient, the movements can be practised at home.

The programme is reviewed and added to throughout the year, with regular visits, every 6-12 weeks, to our treatment centre.

The patient's progress is closely monitored by our specially designed clinical measurement system, so that we can gauge the neurological progress and activities of daily living.

This way of working combines the best of our expertise and a family's love, to provide previously unimaginable progress.

Nonetheless, the treatment is a labour intensive and time-consuming process for both our specialists and the families / carers, which is why it is not provided either by the NHS or private health care organisations.

The Results

Over the last 20 years, we have been able to give renewed hope and happiness to thousands of patients, their families and friends from all around the UK. Our approach helps nine out of ten patients see real improvements - noticeable in everyday life. At the moment, we manage to treat 250 people each year, but we are setting our sights still higher.

*It's not how much we give but how much love we put into giving.
~ Mother Teresa ~*

Our methods usually produce abilities in patients that were not present previously. This, in turn opens doors to the development of still further abilities, gradually helping people to improve the quality of their lives, and so to reach their full potential.

Our work also improves the quality of life of the parents or carers of the people we treat. This manifests itself in various ways from ease of care to renewed optimism and sheer zest for life.

Treating People With Learning Difficulties

BIRD's Learning Development Centre helps children and adults who suffer from a wide variety of symptoms which impair their ability to achieve educationally and may also prevent them from functioning to their full potential in many areas of life.

Sometimes, children may be failing at school for no apparent reason. Others have general learning difficulties, hyperactivity or behavioural disorders and are in mainstream education.

In children, these symptoms may be severe enough to be given specific labels such as dyslexia, dyspraxia, attention deficit disorder, hyperactivity or Asperger's syndrome. Sometimes no clear diagnosis can be made but reading and writing skills may be poor, concentration and attention span is often

short, physical co-ordination can be impaired and behaviour may also be giving cause for concern.

As adults, these early symptoms become less obvious, though there may be the emergence of vulnerability to stress, high anxiety levels, difficulty with social relationships or various neuroses or phobias.

None of these symptoms or conditions reflects the intelligence level of the individual, but they can be a barrier to progress.

Often, these difficulties remain unresolved and their presence may indicate underlying neurological difficulties that have not been diagnosed previously.

If these undetected dysfunctions can be corrected, the individual becomes neurologically "ready to learn" and more able to cope with the demands made by everyday life.

BIRD sets out to detect and then correct these dysfunctions, removing them and allowing the person to function better and to fulfil their true potential.



Transformation

In many cases, people with relatively mild learning difficulties and those who care for them, don't realise that their lives can be completely transformed.



In this Annual Review, you can learn about BIRD's work through the experience of three very different people.

Olivia, Elisha and Jim typify the work we do in three distinct areas. Their stories are by no means unique. There are thousands more people whose lives have been transformed by BIRD over two decades of experience dedicated to constantly improving our unique treatment methods.

When Gilly Dickons was eagerly expecting the arrival of her daughter, Olivia, she was told that the baby would have to be born by caesarean section.

But when she went into labour, Gilly had a natural birth. As Olivia's arrival in the world was imminent, Gilly's contractions stopped, causing alarm amongst the medical staff. Olivia needed to be delivered - quickly.

She was born using the ventouse system, a device that attaches to the baby's head and applies suction pressure to help delivery. This caused Olivia's head to become badly swollen.

"I couldn't believe it when I saw the state of her head - it was bright purple and horribly distended," says Gilly.

That was six years ago.

"I don't know to this day why I didn't have a caesarean. As soon as I was admitted to hospital, my labour was allowed to proceed."

As Olivia grew, her parents watched her development in desperation. Olivia's co-ordination was not what it should be, even as a baby. She was continually restless and wouldn't eat or sleep properly. Her behaviour became increasingly difficult for Gilly and her husband, Ian, to control.

Tragically, she had suffered trauma to the brain during her birth. This had been caused by a shortage of oxygen in her brain, which then became impaired resulting in a loss of co-ordination. Gilly and Ian were completely distraught.

They despaired of what the future might hold for Olivia. For although Olivia was much more capable in her day to day life than many other children affected by oxygen deprivation at birth, there still seemed no way of improving her co-ordination.

By the time she was four, Olivia was having ferocious tantrums that left her physically and emotionally exhausted. She would opt out of any group activity at home or at nursery involving other children and would take herself off on her own. Gilly and Ian later learned that Olivia's brain was simply unable to cope with the noise and visual stimulation the other children presented.

"We thought it would completely blight her whole life and hold her back in all kinds of things, for the rest of her days," says Gilly.

During this time of deep despair, Gilly heard about the work

*Out of difficulties grow miracles.
~ Jean De La Bruyere ~*

The greatest waste in the world is the difference between what we are and what we could become.

~ Ben Herbster ~

of BIRD from a relative and resolved to see if Olivia could be helped.

"From the moment we went to see BIRD, I felt there was renewed hope for Olivia's future" says Gilly.

Dr David McGlown, BIRD's Clinical Director, assessed Olivia and was very hopeful about her chances for improvement using the techniques he has pioneered for over 20 years.

He carefully taught Olivia and her parents a routine to practice each day for an hour. The routine is specifically designed to retrain the brain to process information correctly.

Gilly describes the BIRD treatment as "re-wiring" Olivia's brain. "She was left-footed and right-handed - there was just no balance and co-ordination. The BIRD treatment changed all that. Her reflexes became aligned so her brain is not having to over compensate to correct her movements. She became altogether calmer, tantrums disappeared and we don't have the exhaustion that seemed to result from her brain working overtime."

Olivia had to come into the BIRD clinical centre for regular assessment, reviews and changes to the routine during her course of treatment.

After a year of treatment, the results were miraculous.

"The transformation in Olivia is absolutely unbelievable," says Gilly,

"I cannot believe she is the same girl we first took to BIRD for treatment just 12 months ago! It was hard work, but to say it has been well worth it would be an understatement. It's like she has been given her life back.

"Olivia no longer disappears on her own whilst all her friends play in the garden without her. She is now running around and playing on the climbing frame like nothing ever happened. When she got on her bike and rode it round the garden for the first time, it was wonderful.

"She has riding lessons, swims and even took part in a dancing show. All any parent really wants for their child is happiness and out of all of this, the most important thing is that Olivia is now a very happy and sociable little girl."

Olivia's treatment has now ended and she is busy living the life of a six-year old girl; her co-ordination is just like anyone else's. Her first school report showed her to be above average in all areas and she has even been complemented on her social skills.

Olivia is like many thousands of children born each year, whose brains suffer a deprivation of oxygen during birth, causing disability - the severity of which varies enormously. In Olivia's case, the improvements have been total. At BIRD, we manage to markedly improve the lives of over 90% of the people who come to us.



Unlocking Potential

When people have suffered a severe brain injury, it is often thought that little or no improvement is possible in brain function. Time and time again, BIRD has been able to prove that this is not the case.



The first person to realise that something wasn't quite right with Elisha Edwards was her mother Anna.

This was when Elisha was just a week old.

"From the moment Elisha was born, she seemed to be in pain," says Anna, "she would scream almost constantly until she made herself hoarse. It was a terrifying experience."

Over the weeks and months that followed, Anna's worst fears were realised. Elisha was constantly ill and seemed always to be in severe pain. She would become exhausted by throwing herself around violently and never seemed a happy gurgling baby as her older sister Grace had done.

Elisha underwent a series of medical tests. She had complex personality disorders and a range of disabilities and illnesses such as partial deafness - though there was no single diagnosis for her condition, nor was there a prognosis for the future.

By the time she was 14 months old, Elisha hadn't developed at all from the new-born baby stage, but was still showing the same signs of intense frustration and inexplicable anger with the world. At this time, her kidneys failed and she became acutely ill.

Although Elisha came through the illness, her behaviour afterwards was worse than ever. This deterioration continued unabated over the next two years as Anna sought assistance from all quarters - to no avail.

In desperation, Anna enrolled Elisha in a school for children with special needs, where she made a little progress, though she remained severely disabled.

Elisha was four by the time she came to BIRD for treatment. She was seen by Dr David McGlown, the Clinical Director.

When Anna first spoke to David, she was at her lowest ebb.

"As I spoke to Dr McGlown, I realised that for the first time since Elisha's birth, somebody at last seemed to realise what I was talking about. He asked questions about her behaviour and described symptoms typical of the type of child Elisha is. It was just like he was describing Elisha herself. This was both a revelation and an enormous relief to me. To know that someone out there knew what I was going through made me feel for the first time, that we weren't completely alone.

During Elisha's initial consultation in November 2001, Dr McGlown realised that she was an extreme case.

There comes that mysterious meeting in life when someone acknowledges who we are and what we can be, igniting the circuits of our highest potential.

~ Rusty Berkus ~

"Her behaviour was at the absolute outer boundaries of what we're used to dealing with", he said. "She would scream almost constantly and throw tremendous temper tantrums every few minutes. Even more worryingly, she would frequently lash out at others and attack herself. She couldn't walk independently and was very limited in the use of her hands. She was unable to communicate well - using only single words. Her attention span was extremely short, making it virtually impossible for her teachers to help Elisha make any educational progress whatsoever.

"Many of the children we have treated over the years have shown similar problems to Elisha, but not many have displayed all these developmental disorders at once."

After Elisha had been assessed by Dr McGlown, Anna and her husband Ifor were taught how to carry out a half-hour daily developmental routine with Elisha, which they could do at home.

BIRD's treatment takes the brain back to its basic development with premature reflexes which children like Elisha have never learned how to inhibit as they grow. The specifically designed exercises gradually "re-educate" the reflexes. Anna and Ifor were absolutely determined that they would follow the exercises to the letter in what they saw as a last-ditch attempt to improve Elisha's life.

"I'm not the type of person to look for miracles, but nothing prepared me for the instant and profound effect that the treatments had on Elisha. The improvements were really quite staggering," says Anna.



"Her speech became clearer from the start, the tantrums gradually stopped and by Easter she was walking with a frame. When one of her teachers said "what's happened to Elisha - she's different!?", I knew we were on the road to recovery.

"Since the BIRD exercises began, I can quite honestly say that there have been improvements week-on-week.

"I would have gone to the other side of the world to help my daughter, but in the end, I only had to travel 20 miles down the road. I simply can't understand why more people don't know about the wonderful work being done by BIRD."

Elisha's story is typical of many of the children who come to BIRD with severe brain injury. These children can never be healed, but their lives - and therefore the lives of their families or carers - can be improved beyond all recognition by our unique approach.



Continuous effort, not strength or intelligence is the key to unlocking our potential.
~ **Liane Cardes** ~

“Lost Causes” ...?

Each year, in the UK, around 134,000 people suffer a stroke. Strokes happen to people of all ages, but are more common with advancing age. The effects can be devastating. The recoveries can be remarkable...



When Jim Fieldsend was just 48, he developed a severe headache. As the pain worsened, he was taken to hospital where it was found that Jim was having a brain haemorrhage. During the operation to relieve the pressure on his brain, Jim tragically had a massive stroke, which impaired his brain and totally paralysed the left side of his body.

That was nine years ago.

The months in hospital that followed are an all too forgettable blur in Jim's memory. From being an agile man with a quick mind and vibrant personality, Jim now found himself almost completely paralysed and in residential care.

He was told that he would improve no further.

During this time of deep despair, one of Jim's regular visitors was Jean, who remembers being appalled by the deterioration from the man she had known before the stroke.

“Despite everything, Jim somehow managed to continue to be the

incredibly funny man he had been before.” says Jean. “His lively personality still shone through his severe physical disabilities.”

At this time, Jim could move only his right arm a small amount and it was difficult for him to communicate, though he could make himself understood.

“Basically, I had a lucid mind in a vehicle that just wouldn't function properly ” he says.

Jean continued to visit Jim regularly and successfully lobbied for him to be moved to a residential home nearer to her own home. As the visits continued, Jim's spirits gradually rose and he and Jean found themselves becoming closer and closer.

In 2000, Jim and Jean heard about the work of BIRD via the Stroke Association and decided to give it a go.

“That was the second best decision I ever made,” says Jim. “The best was asking Jean to marry me. She said yes as long as I lost weight and made enough progress with the BIRD programme to be able to do

as much as possible for myself! That was all the incentive I needed.”

Jim moved into a specially-constructed extension at Jean's guest house and took up the BIRD programme in earnest.

As BIRD's Clinical Director (Designate), Stephen McQue, explains, telling the victim of a severe stroke like Jim to move in a certain way is like telling a new-born baby to 'get up and walk'. “The brain needs to go back to its primary development. Jim had to re-learn his basic instincts. The exercises we taught Jim to do are specifically designed to do just that. To make even a small amount of progress takes many, many hours of hard work and dedication. Fortunately, Jim was absolutely determined to succeed.”

The proof of the pudding was certainly in the eating for Jim. He was nine months into the treatment before improvements really began, when he became able to move his paralysed left leg slightly under his own control.

Jim's brain had begun to forge new pathways.

After eighteen months Jim can stand and his ability to control his own body is growing by the day.

“His progress has been quite remarkable and is testament not only to Jim's hard work, but also to Jean's” says Stephen McQue. “It takes two people to do the exercises and Jean has been a steadfast and willing trainer for Jim throughout his rehabilitation.”

Most importantly of all, Jean was as good as her word and the two were married in August of this year. Jim was able to stand by Jean's side, unaided, to take his vows. Not only

that, but he was also able to make the wedding cake!

"I can't begin to express how my life has been transformed over the past 18 months" he said. "At our wedding, my son thanked Jean for giving his father back his life - I could say the same to the people at BIRD. When I was in residential care, I was written off as a lost cause. Now, I play wheelchair tennis, go sailing and fishing and hope to be able to walk again one day."

Jean and Jim's gratitude to the organisation that gave him renewed hope was such that they asked wedding guests not to buy presents, but to make a donation to BIRD instead.

The final word goes to Jean who can see the transformation in Jim more clearly than anyone.

"After the stroke, Jim couldn't move his body. Now he can. It's that simple. The improvements are down to the dedication and expertise of the BIRD staff and Jim's determination to succeed. His mobility and ability gets better by the day. It is wonderful to see my husband rediscovering life."

Many stroke victims, like Jim, could benefit hugely from BIRD's unique approach to "re-educating" the brain. It is a tragedy that simply not enough people know what improvements are possible in this way.



MONEY MATTERS!

Financial highlights for the year ended 30 September 2002:

Income:

| | |
|------------------------|----------|
| Income from patients | £171,811 |
| Restricted donations | £103,921 |
| Unrestricted donations | £295,851 |
| Social fundraising | £1,087 |
| Interest | £7,501 |
| Total | £580,171 |

Expenditure:

| | |
|-------------------------|----------|
| Direct costs | £386,558 |
| Admin costs | £19,776 |
| Fundraising expenditure | £78,462 |
| Total | £484,796 |

Surplus for the year £95,375

JOIN THE FAMILY

We rely totally on charitable donations to fund our work and don't receive any statutory funding.

EVERY PENNY REALLY COUNTS

As we are a small charity with just 10 staff, we are able to keep administrative costs and overheads to the bare minimum. Consequently, almost all the money we receive is spent directly for the benefit of the people we are here to help.

If you would like to help us provide our unique service to brain injured children and adults, then we guarantee that your money will help make a real difference.

For advice on ways you can help us to raise money, please contact John Williams.

WHERE THERE'S A WILL, THERE'S A WAY

Leave a bequest in your will. For a free guide to including a gift in your will to BIRD please e-mail John Williams at the address below or write to him at the address overleaf.

If you would like to help or can think of other ways supporting our vital work, contact:

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No Looking Back

If you would like to learn more about any aspect of our work, then please get in touch.

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BIRD

brain injury rehabilitation
and development

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