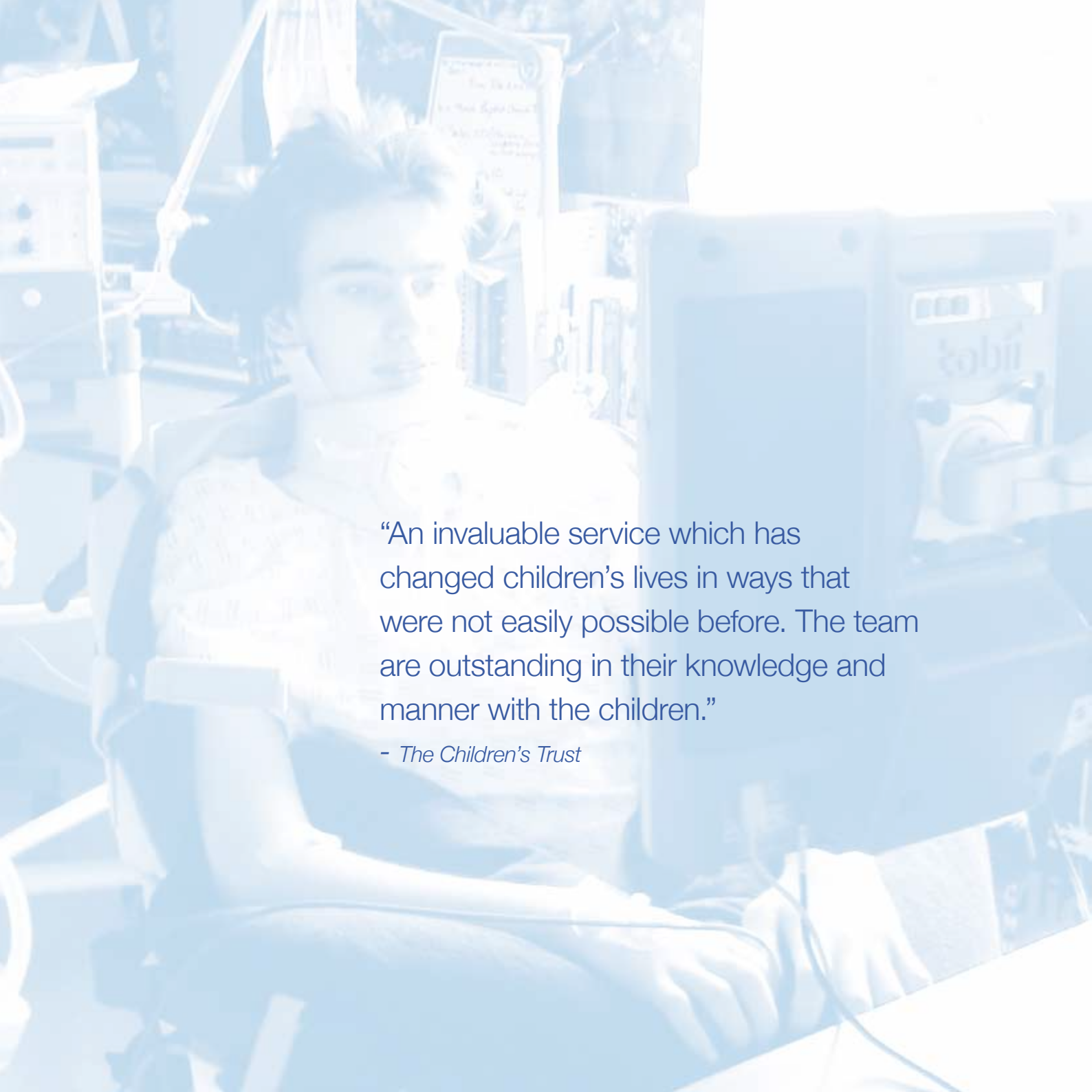




# StarGaze+

You wake up after an accident.  
You realise you can't move  
and you can't speak.  
That's when we can help.

 *Special Effect*

A young boy with dark hair is sitting in a hospital bed, looking off to the side with a thoughtful expression. He is wearing a white hospital gown. The background is filled with medical equipment, including a monitor and various machines, all rendered in a light blue tint. The overall atmosphere is calm and clinical.

“An invaluable service which has changed children’s lives in ways that were not easily possible before. The team are outstanding in their knowledge and manner with the children.”

- *The Children’s Trust*



**Matt Hampson**, ex-England Under-21 rugby player, suffered a major spinal injury while training in 2005.

*“When I regained consciousness I couldn’t move and I couldn’t speak – all I could do was move my eyes. It’s impossible to explain the fear, desperation and helplessness you feel when you’re totally unable to communicate.”*

The 2011-14 StarGaze+ project will make the crucial intervention for people in this situation. It will provide the loan and support of cutting-edge equipment, operated purely by eye movement or brain stimulus, that allows a vital means of ‘speaking’ to medical staff, family and carers.

As you’ll see in this booklet, it isn’t just those with spinal injuries who you’ll help by supporting this project. StarGaze+ will enable the SpecialEffect team to transform the lives of people of all ages with the most severe disabilities, freeing them to communicate when they have no voice of their own.



## Alex

Travelling isn't easy for Alex so he has to spend nearly all of his time at home. As a result, his computer has become increasingly important as a link to the outside world. However, due to his condition, control of the computer was becoming more and more difficult. The loan of a gaze-controlled computer made a huge difference and he was soon using it to play many of the games he'd always wanted to play, like Football Manager 2011. Gaze-control was also a key factor in enabling him to be accepted for an online course on games design.

At the age of two, Lewis was bitten by an insect while on holiday, and three years later he's now paralysed, unable to speak and only able to move his eyes. We loaned him a gaze-controlled computer and created special games containing all his favourite TV characters. Buying and supporting a gaze-controlled computer is expensive – up to £20,000 – but, for Lewis, it's been life-changing.



## Lewis



## Gina

Gina is a teenage girl whose road traffic accident left her brain-damaged with severe physical disabilities and unable to speak. She was finding it extremely difficult to control the computer and was becoming less and less motivated, but took to gaze-controlled technology immediately. With our support and training, her support staff were able to build on her use of the system to enable her to communicate as well as enjoy leisure activities, especially music. She's pictured here playing the saxophone with her eyes!

# What is StarGaze+?



Like Matt, tens of thousands of people each year suffer a stroke, traumatic injury or degenerative illness that leaves them completely paralysed<sup>1</sup> – unable to move any part of their body other than their eyes.

The purpose of the StarGaze+ project is to loan and support gaze-controlled technology for these people when they need it most – *immediately* following their personal tragedy. This equipment will enable these people to operate a computer for communication, independence, work and leisure.

StarGaze+ builds on the hugely successful StarGaze pilot project, which also provided gaze-controlled technology to many people in hospitals and care homes. The pilot project highlighted the fact that there are a number of paralysed people whose vision is not good enough for gaze-control and for whom another solution needs to be found. So as well as expanding highly effective loan and support of gaze-controlled technology, StarGaze+ will provide additional cutting-edge technology such as brain-control.

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<sup>1</sup>It's estimated that there are **approximately 1.5 million people** in Europe who have either a spinal cord injury, brainstem stroke or traumatic brain injury. For a significant number of these, their eyes are the part of their body they can control most effectively. (Taken from Jordansen, I.K., Boedeker, S., Donegan, M., Oosthuizen, L., di Girolamo, M., and Hansen, J.P. (2005), from "Report on a market study and demographics of user population" IST-2003-511598: Deliverable 7.2 [www.cogain.org](http://www.cogain.org))



## Who are SpecialEffect?

And why are they the best organisation to carry out this project?

Gaze-control and brain-control are new and very expensive technologies. They require expert support and care if they are to be used effectively in a hospital or domestic situation. **SpecialEffect** is a charity dedicated to helping disabled people benefit from advances in just such technology, and they have the expertise and experience to be able to give the best support possible.

Dr Mick Donegan, the Director of SpecialEffect, is widely recognised as a world-leader in gaze-controlled technology. He played a key role in the EU-funded project studying gaze-controlled technology – COGAIN ([www.cogain.org](http://www.cogain.org)). and has published widely on the subject. He is also Adviser to the TOBI project ([www.tobi-project.org](http://www.tobi-project.org)), an EU-funded project investigating brain-control and disability.

But the overwhelming reason why SpecialEffect is the best organisation to carry out the project is because they are independent specialists who only want the best for their client group. They have no commercial ties or obligations – they're simply guided by what's in the best interests of the people who need their help.

Find out more about SpecialEffect at [www.specialeffect.org.uk](http://www.specialeffect.org.uk)

# What is the aim of the project?

During the loan of a gaze or brain-controlled computer it's confidently anticipated that the patient's quality of life will improve considerably. They will also have had the time and support necessary to discover if the technology would have longer-term benefits. This evidence will be crucial in their efforts to fundraise for themselves or apply for statutory funding. Once their own equipment is in place, the SpecialEffect system can be loaned to another person and the training, support and personalisation process can begin again.

At present, gaze and brain-control is very expensive and such systems are rarely found in hospitals. As well as helping the individuals directly involved, there will be a powerful 'ripple effect' that will spread information and expertise throughout the medical world and among others providing support to disabled people who could benefit from this technology.

So the aim of the project is simple. By providing the specialists and equipment required, StarGaze+ will demonstrate to all concerned what can be achieved by using the most advanced and powerful technology in the world, supported by some of its leading specialists, to help those who need it most.



contact **mick donegan** at [info@specialeffect.org.uk](mailto:info@specialeffect.org.uk) or tel **01608 810055**



## How will the project work in practice?

When a system is required, the hospital will contact **SpecialEffect**. They will work with the medical team and family to provide the training and support that ensures that the patient has a personalised and fully-functioning system as soon as possible.

The project will last for three years, beginning in August 2011 (dependent on funding), commencing with the purchase of cutting-edge gaze and brain-controlled systems.

- Any hospital in England will be able to contact SpecialEffect to ask if an individual can be helped through the StarGaze+ project.
- Following an enquiry, the SpecialEffect team will make a visit to evaluate whether a gaze or brain-controlled computer system will be of benefit. If so, initial setup of the equipment will be made on-site to ensure that the person involved gets off to the best possible start.
- During the loan period the SpecialEffect team will liaise on an ongoing basis with the professionals, family, carers and, of course, the person using the equipment themselves to make sure that it becomes an increasingly personalised and useful tool with which they can achieve ever-greater success. Additional online support will be provided between visits by telephone, email and remote computer control.
- If the loan period is proving to be successful and the future purchase of a gaze-controlled system is being considered, the person involved and those supporting them will be given independent advice by the SpecialEffect team in relation to potential suppliers.
- If a gaze-controlled system is subsequently purchased, SpecialEffect will continue to provide liaison and support for everyone involved, including the equipment suppliers, to make sure that the individual makes a smooth transition from a SpecialEffect loan system to a system of their own.

- Working on a loan period of approximately three to nine months, it is anticipated that up to 36 severely disabled people will be able to benefit directly from these loan systems over the three years of the project. By training hospital professionals directly under the project, through dissemination at conferences, the SpecialEffect website and the media, the results will influence the future opportunities for the estimated 1.5 million people in Europe who might benefit from such state-of-the-art technology.

## How will the success of the project be evaluated?

- Ongoing liaison and evaluation will take place between SpecialEffect, each user and those supporting them during each support visit and during online support (email, telephone, etc).
- Outcome questionnaires will be completed by the participant and/or those supporting them on completion of the loan.
- All feedback will be evaluated and a report (with recommendations) will be produced at the end of years one and two, and on completion of the project.
- The results of the project will be shared through the SpecialEffect website, publicity (TV, radio, press) and through international conference presentations.





## More about Matt

Matt's quadriplegia, sustained after suffering a spinal injury playing rugby in 2005, has not blunted his ambition, Matt, pictured here on the left with SpecialEffect Director Mick Donegan, currently writes a column for the Leicester Mercury, assists with coaching at Oakham Rugby Club and aims to contribute heavily to spinal research. He is the patron of SpecialEffect.

# Budget

Developing StarGaze+ will cost a total of £316k. The project team have detailed costs and a full project plan for inspection.



|  | £k              |
|--|-----------------|
| <b>Trialling of systems and support</b>  | 55,650          |
| Training, home and hospital visits, plus face-to-face and online support provided by specialist occupational therapist, research and development coordinator, and senior assistive technology specialist.                |                 |
| <b>Research and development</b>  | 39,750          |
| Identifying, modifying, adapting, developing and testing customised equipment and software at the SpecialEffect Centre.  |                 |
| <b>Loan equipment</b>  | 108,000         |
| Gaze and brain-controlled gesture and movement recognition systems.  |                 |
| <b>Additional software and accessories</b>   | 15,000          |
| Including specialist software (eg on-screen keyboards) adapted for individual users.   |                 |
| <b>Dissemination</b>   | 30,000          |
| The findings of the project, along with the software developed through it, will be published online on a regular basis. In addition, staff will disseminate results at meetings and conferences.                         |                 |
| <b>Carriage of loan equipment/travel</b>   | 15,000          |
| In addition to travel for supporting the professionals and individuals involved in the project, close collaboration with suppliers and universities (both in the UK and abroad) will be an integral part of the project. |                 |
| <b>Overheads @ 20%</b>   | 52,680          |
| <b>Total target</b>  | <b>£316,080</b> |



“The StarGaze Project is giving many people who have been paralysed through a traumatic injury or illness the opportunity for communication and hope at a time when they need it most.”

- David Cameron



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