



newlife  
foundation for disabled children



Annual Review 2008/2009



**Catherine**  
Aged 2, Cornwall

## The Child **Always** Comes First

Founded in 1991 as the Birth Defects Foundation by a small group of parents, doctors and business people, Newlife Foundation for Disabled Children is committed to providing support to the health and welfare of children with disability.

In 2008 we widened our remit to become Newlife Foundation so that we can put the child and not the cause of the condition at the centre of our work. Disabled children are at the heart of Newlife. Their needs, challenges and rights drive and focus our work. At the same time we support and inform their families and bring quality of life and hope.

Newlife is a highly effective charity with a surprisingly wide reach and remit, providing a 'one stop' service for disabled children and their families.

**There are four main elements to Newlife's work:**

**Equipment provision:** Newlife is passionately committed to providing the equipment disabled children need quickly, appropriately and without prejudice.

**Nurse Service:** qualified and experienced Nurses are dedicated to providing excellent confidential support to parents, families and carers. Nurses also guide our Equipment Grant Service.

**Campaigning and Awareness:** to get a fairer deal for disabled children at a national and local level. To get the provision and support each child and family deserves and is entitled to. Awareness is targeted to help overcome family isolation and inform professionals.

**Medical Research:** Newlife funds pioneering medical research to improve child health, reduce incidences of inborn conditions, improve diagnosis and lead to more effective treatments for children.

“We feel strongly that children like Catherine need all the love and support they can get.”

*Catherine's Mom*

# A Year of Change...

This year was a year of change for the charity and of course change brings challenges. Some of the changes were about the world we live in; a recession that no one believed would cut so deep hit the world and challenge our fundraising plans, but we persevered.

We also changed our name and widened our remit so we could help more disabled children, regardless of the cause of their disability. We believe the number of disabled children in the UK is on the increase. This means more families need our Nurse support services and more children are in need of Equipment Grants, as many families are stretched through unemployment. More research applications were received this year than ever before, as the financial climate deteriorated and researchers faced challenges finding funding to improve child health.

Sadly we also saw more resistance from Statutory Services to provide essential equipment. So our campaigning and intervention work was challenged to persuade them of their proper responsibilities and work with them to overturn unreasonable decisions to refuse provision. So a year of change and challenge, but nothing we face compares to the challenges every disabled child faces daily. That's why Newlife exists and why this year we have faced the challenges with determination and continued to put the best interest of the child and their family first. Newlife Foundation for Disabled Children is not just a name change, it's a declaration, we are here for all disabled children and through Newlife we aim to give them new hope.

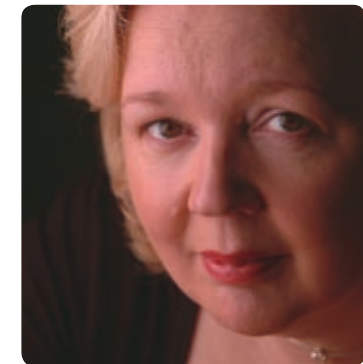
## Thank you for making time for disabled children.

None of the challenges we face could be achieved without our supporters; individuals, volunteers and companies who allow us to deliver the actions and services we pursue every day. Thank you are small words, but I do hope all supporters know that through Newlife your support really does touch the lives of individual children, so from them, myself and the Trustees, I extend sincere and enduring thanks.



**Mrs. Sheila Brown, OBE, FRSM**

Chief Executive Officer



# Equipment Grant Service



## Equipment Grant Action

In 2008/2009 Newlife provided 736 children with equipment, an increase of 3.7% on the prior year.

Every Newlife grant is based on an assessment by our Nurses who look at the individual needs of the child and their family. Backed up by a health or social care professional recommending a specification, every application is first of all assessed for urgency and if the need is acute the application is fast tracked. This often means it can be agreed on the same day it arrives. In this year Newlife made 22 priority Equipment Grants which released children from hospital and responded to urgent worsening of conditions or emergency situations. Every grant application is dealt with by a Nurse and the application system is simple. Grants achieve all sorts of benefits:

- Improve mobility
- Provide comfort and pain relief
- Aid development of therapy
- Ensure safety
- Provide a better quality of life/dignity or life experience

Many items have dual or several benefits. For example a bed can provide relief of pain, aid in therapy through a special mattress with built in massage which can reduce distress and stimulate muscles or have side supports that can stop a child falling. Facilities such as height adjustment can aid families to administer treatment, comfort or lift the child without hurting their back. So one item, but many benefits for the child and family.

### Mobility

Newlife provided 378 items of mobility equipment this year. This includes wheelchairs but also a large number of car safety seating, specialist buggies and support walkers. Such equipment enables and gives freedom allowing children to access their community, attend school, participate in the enjoyment of life and develop strengths.

### Seating and Beds

Newlife provided 93 items of seating and beds. Ensuring spinal support is crucial to prevent conditions worsening. Many children experience pain from sitting for many hours a day and are at risk of worsening conditions without the right seating. Beds also provide excellent

“The postural support helps our son to relax - causing less pressure on his stomach muscles to stay sitting upright. When we need to go out the double buggy has helped with being able to transport both our son and his younger brother - which has reduced my back strain. It has also helped to reduce the pressure on our son’s joints which has decreased the amount of pain he experiences.”

pain relief; many children spend many hours in bed and suffer disturbed sleep or pain and pressure sores from lying in a poor position for hours at a time. These specialist seats and beds are essential to a child’s health and relieve their pain.

### Development and Therapy

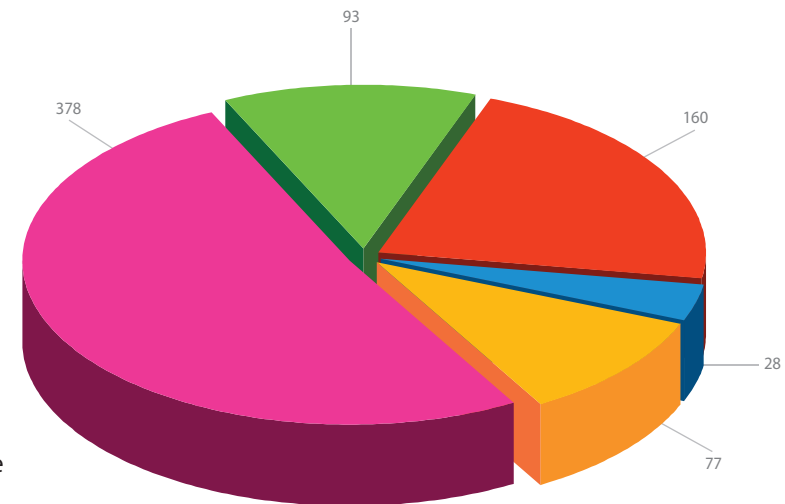
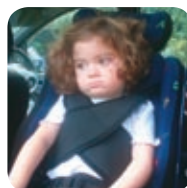
Newlife provided 160 items of development and therapeutic equipment. This could be equipment to stimulate children who are visually or sensory impaired, equipment to calm and soothe distress and equipment to aid therapy and learning. In the face of complex disability, equipment can deliver ways to reach out and move forward in a child’s life.

### Safety equipment

Newlife provided 28 items of safety equipment. This includes safespace equipment for distressed children and those needing behavioural safety care. Equipment such as hoists help to move a child safely and carefully without risking injury to either the carer or the child. Toileting and bathing equipment can prevent falls and increase independence. Crash mats give safety for a child with seizures or lack of danger awareness. Many children with disabilities need a specific response to protect them and their carers from injury and danger and Newlife Grants provide this.

### Specialist clothing, bedding and household goods

Newlife has provided 77 such items. Special body splinting can assist children with poor muscle tone to walk and move better. Children with bowel or bladder problems cause damage to their clothing and bedding. Most families live in average sized homes and accommodating bulky therapy equipment in a home, or oxygen cylinders, specialist dressing etc is just impossible so external storage is provided in some cases. These are the practical items of daily life that many people would not appreciate and without which can cause serious difficulties. Imagine storing several hundred incontinence pads all delivered at once in an average home. Newlife Grants provide practical help for real life problems.



Type and Value of Equipment Grant Scheme  
1st April '08 - 31st March '09

	No. of Grants
	2008/09
Mobility	378
Specialist Beds / Seating	93
Developmental / Therapy	160
Safety	28
Specialist Clothing / Bedding Household	77
<b>Total Number of grants</b>	<b>736</b>
<b>Value of grants</b>	<b>£944,318.53</b>



# Nurse Services



The Nurse Services and Equipment Grants Service together form a comprehensive service and wide-ranging 'one-stop' service to families nationwide.

It is a service that can be easily accessed by all, regardless of social economic status. The use of translation services and advocates means that the service can respond to all sections of society.

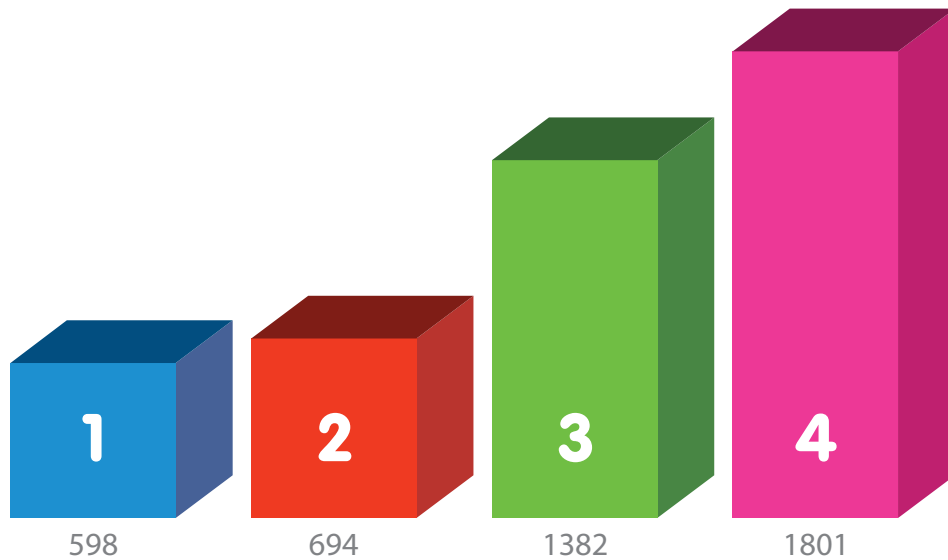
Newlife believes that families and their children deserve excellent services delivered by qualified and experienced staff. At Newlife, our nurses listen, understand and care. Contactable via freephone, website or email, Newlife nurses are 100% dedicated to providing an excellent and confidential support and advisory service to parents, families and carers.

“...Brilliant, just to be able to call the Nurses is a relief. At last we have someone battling in our corner, someone who understands the systems and can see me through this journey”

In the last year Newlife nurses helped families with many issues including:

- People planning pregnancies who are concerned about conditions - especially genetic disorders.
- Foetal anomalies discovered in pregnancy.
- Parents concerned about finding a diagnosis for their child's condition.
- Recently diagnosed families looking for information and specialist support.
- Crisis and bereavement.
- People who need to source vital equipment.
- Concerns about a child's worsening or changing condition.
- Advice on understanding medical terminology.
- Information on which specialist can assist and how to access services.
- Referrals to other services and organisations.
- Information on rights and statutory provision.

In total this year, 4,475 people were helped through this valuable service.



## People Helped through Nurse Services per Quarter during 2008/09

### Important Questions

Every day our Nurses are asked questions that are important in the life of a family, caring for a disabled or terminally ill child, such as:

Is there someone who can help me understand and manage my son's Autism?

I cannot get any respite care, what can I do? Where can I find hospice care? The doctor said she has this condition, but what does this word mean? What can I do when my little girl is in pain? He's 16 and needs help

toileting, any ideas to protect his privacy? Where can I get underwear that will fit over my son's spica plaster? I don't know where to turn, I can't cope and feel so alone, I know he hasn't got long left but I just can't bear losing him, what can I do?

These, and hundreds of other questions, many about equipment, others that are spoken through tears or as words of desperation, are responded to by our Nurses. Practical help for real families, delivered by caring Newlife Nurses.

“Every day I hear of a disabled child who is needlessly suffering,”  
Newlife Nurse



## Campaigns, Intervention & Awareness



Newlife's work in these areas is vital and underpins both the Equipment Grant Service and the Nurse Service. There are three distinct areas which, although they can overlap, are essentially different in nature:

### Equipment Provision Campaign

By highlighting the failures of the current system and the effects it has on children and their carers and through promoting best practice, Newlife's goal is to get a fairer deal for disabled children in respect of equipment provision through statutory services.

Following the 'It's not too much to ask' campaign report in 2007, Newlife continues to campaign to improve the provision of equipment to children with disabilities.

### In the last year Newlife has achieved:

- 37,000 signatures to a petition calling upon all statutory service providers in the UK to prioritise the provision of equipment for disabled children to fully ensure that their health, care and needs are met.
- The tabling of 2 Early Day Motions (EDMs) asking Government to ensure that disabled children are properly provided for in terms of their individually assessed need and that criteria for equipment are standardised to put an end to the current postcode lottery of provision.

- Gained recognition by the Department of Health as a leading authority in the provision of equipment to children with disabilities.
- Gained recognition as a key stakeholder in an ongoing Government consultation called 'Transforming Community Equipment and Wheelchair Services'.
- The publication of a detailed campaign document containing legal advice from a leading barrister, and distributed it to almost 4,000 people.
- Writing to all Local Authorities and Primary Care Trusts (PCTS) to request that they improve performance in areas such as; monitoring unmet need locally, improving assessment times, improving local budgeting to ensure funds are available and developing fast track services for those in urgent need.

As a result of the last activity some changes have been made around the UK and Newlife will continue to press for more in 2009/2012.

## Equipment Intervention Activity

Acting on behalf of families/children who face delays and refusals from statutory services to provide the equipment they so badly need.

When applications are received for equipment, they are reviewed and where it is felt that statutory services have a responsibility to provide the equipment, Newlife will contact them and attempt to get the funds provided.

This intervention can achieve several outcomes. For example, it increases the awareness of the statutory body of their obligations to provide the equipment.

Additionally, if Newlife is successful in leveraging some or all of the funds from the statutory body, Newlife funds can be used elsewhere to provide more equipment. These 'leveraged funds' do not come through Newlife accounts but are clearly an outcome for the organisation and the children and families we serve. In the last year nearly £25,000 was 'rescued' in this way.

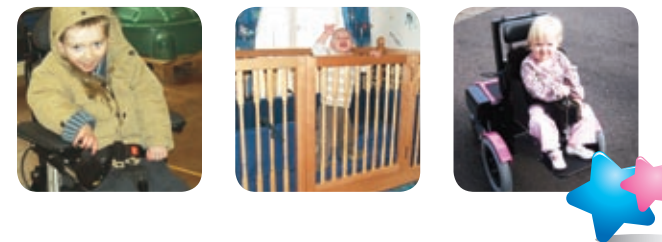
Intervention also helps us discover the reason/s why the statutory body is refusing to fund thus enabling us to challenge locally made policies. Last year we intervened in individual cases on behalf of families and were successful in getting many 'restrictive' policies reviewed and changed so that in future locally set criteria will not prevent provision.

## Notable examples include:

In the South of England, a Primary Care Trust (PCT) refused to fund an application for specialist lycra splinting costing £1,890. Newlife challenged the decision on behalf of the family and this led to the equipment being provided by the PCT, which has subsequently contacted all the relevant departments explaining that money is now available for this type of equipment in this area.

In the North West of England Newlife intervened on behalf of a family who were refused a specialist car seat by their local PCT. The PCT provided the car seat after Newlife made the case for the child. This marked the first statutory body changing their policy to provide a car seat to a child with disabilities and will be used as an example of best practice when we challenge other areas regarding their car seat provision policy.

These successes and more are evidence that Newlife is not content merely to provide the equipment but is determined to challenge policies on a local and national level. Much more work is needed in this area to ensure that restrictive criteria and failure of provision continue to be challenged.

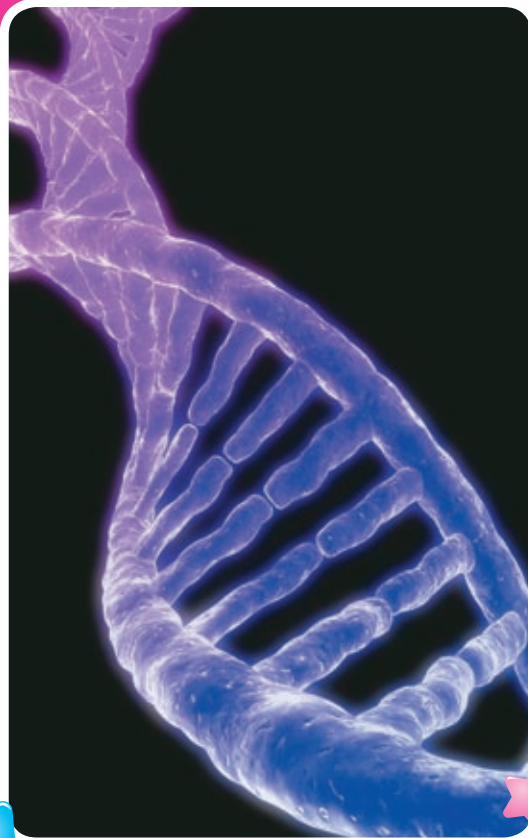


## Targeted Awareness

Newlife's aim is to highlight the incidence, effects and impact that disability and terminal conditions can present to people. This work is targeted to the general public and to the relevant health, welfare, care and education professionals. Last year, approximately 18,000 professionals were reached through professional conferences.



# Medical Research



Over 18 years, Newlife has funded a body of research that has found genes, aided diagnosis, developed new tests...

and added to the building blocks of knowledge to increase understanding and responses to conditions... giving hope around the UK to families and children affected by inborn conditions. Medical research has proven it is the key to improving child health. Investment in prevention and understanding conditions means we can not only improve detection and diagnosis, but we can also improve management, treatment and prevention in the future.

## Summary of Newlife Full Grant Research Commitments in 2008/2009:

Out of the 37 grant applications received in the year, Newlife has committed £555,954 to six projects:

**Childhood Blindness:** Definition of the genetic basis of cerebroretinal microangiopathy with calcifications and cysts  
*University of Manchester £68,325*

**Respiratory Disease:** Identification of disease genes of Asphyxiating Thoracic Dystrophy (Jeune Syndrome)  
*UCL, Institute of Child Health, London £55,448*

**Complex Disorders:**  
Investigation of the genetic basis of congenital hypopituitarism in a cohort of patients with complex developmental disorders  
*UCL, Institute of Child Health, London £120,000*

**Smith-Lemli-Optiz Syndrome:**  
Does defective lipid transport and NPC1 function play a major role in the pathology and dysmorphology of Smith-Lemli-Optiz syndrome?  
*University of Oxford £74,052*

**Netherton Syndrome:**  
Gene Therapy for Netherton Syndrome  
*UCL, Institute of Child Health, London £118,131*

**Bardet-Biedl Syndrome:**  
Investigating the role of Bardet-Biedl Syndrome Type 9 as a key link between ciliopathy syndromes  
*UCL, Institute of Child Health, London £119,998*

## Summary of Newlife Start Up Grants 2008/9:

**Bone deformities in the foot:** Creating a model for clubfoot (talipes). *University of Aberdeen £8,794.*

**Eye Malformations:** Homozygosity mapping to identify recessive genes for congenital eye malformations. *Oxford £14,960*

**Ovarian Dysgenesis:** Familial Ovarian Dysgenesis – an investigation into genetic causes. *University College Hospital London £14,757*

**Pallister Killian Syndrome:** Identification and prevalence calculated of Pallister Killian syndrome. *Princess Anne Hospital Southampton £14,000*

**Craniosynostosis MRI:** Magnetic Resonance Imaging as a diagnostic & planning tool in craniosynostosis and orthognathic surgery. *Oxford £15,000*

**CMN Research Clinic:** Investigation of the genetics of Congenital Melanocytic Naevi (CMNs). *Great Ormond Street Hospital £2,000*

**Genes in hypothyroidism:** Identification of new causative genes and genotype/phenotype correlations for congenital hypothyroidism. *Birmingham Womens Hospital £14,985*

**Lissencephaly MRI:** Prenatal diagnosis of lissencephaly by in utero magnetic resonance imaging. *University of Sheffield £14,400.*

**Stem cell transplantation:** In utero transplantation of autologous amniotic fluid stem cells. Preclinical study in a large animal model. *Great Ormond Street Hospital £15,000*

**European Society of Human Genetics:** Noonan Syndrome research collaboration meeting. *St Georges Hospital London £2,000*



## Hope through Research

Another important aspect of Newlife's research commitment is Researcher Training to ensure that qualified and experienced staff are in place able to focus on areas of child health. To that end Newlife funds a BSc/MRes Course that provides training in the field of congenital abnormalities and genetics at St Georges University of London.

Since 1997, 60 students have now completed the full BSc and are now either finishing their medical degrees or in the early stages of their training. A number have started in paediatrics or genetics. In the first two years of offering the Birth Defects module to a wider group of students, 14 took it in the first year and 18 last year. In the coming year, about 20 students have registered for the course. In the first year of the MRes 6 students took the Genetics Course, this rose to 8 in this year. This training continues to be offered at PhD level - In the year 08/09 one student successfully completed this study and obtained her PhD for gene mapping studies on neurodevelopmental disorders in the Amish population. One student will commence a PhD on imprinting disorders causing failure to thrive and short stature.

The Foundation has for some years had a particular focus on research into Noonan Syndrome and in the past year has made two new commitments in this area:

- Noonan Syndrome Unit at St Georges Hospital London - £18,000 to continue the work.
- PhD Noonan Syndrome Joint Pain - £6,000 to research this issue, which affects mainly young adults and adults with Noonan Syndrome, also at St Georges Hospital London.



# Fundraising Plans



## Newlife National Appeal 2009/2012

Demand for Newlife services is increasing. Between 2006 and 2008 applications for Newlife Equipment Grants increased by 20% and we anticipate that demand for Newlife Services will grow by a further 30% between 2009 and 2012. In addition, this year we saw a major increase in the number of research applications. Our nurses and campaigning activity are also being used heavily by more families every year. To meet these growing needs, Newlife has launched a National Campaign with three clear goals and we need to raise funds in each of the three key areas.

**All funds raised through the National Appeal are legally 'restricted'. This means, nothing can be taken out for costs, admin etc. This gives the donor the right to tell Newlife how they want the funds they have given to be spent. We give a guarantee that 100% of a National Appeal gift will be spent according to the donors wishes.**



“there is no better way to reach out to a child then by giving to Newlife, I give because I know every penny is used to touch a child's life”  
*Newlife Supporter*

# 100%



### The Disaster Appeal

To prevent an imminent personal disaster for our most vulnerable members of society. We will provide an average of 75 pieces of equipment per month; wheelchairs, beds, walking frames, sensory aids, safety aids and basic everyday items to make children safe, comfortable and to maintain their dignity. We will need £100,000 every month to meet the increase in demand for equipment.



### Mission Possible

There are 770,000 seriously disabled children in the UK. It is possible to support every one of these families. Newlife Nurses reach out to these families via a freephone hotline, providing a lifeline of advice and direction. Our Mission Possible Appeal will fund this vital Nurse Service – working directly with families, but also supporting health professionals and Local Authorities to make the very best of the limited resources available in the UK. £150,000 will ensure the continuation of this vital service for one year.



### Real Research

Medical Research can hold the key to improving child health and preventing disability and conditions that can strike any family, at any time. The Real Research for Real Children Fund will fund medical Research that can be translated into best practice by health professionals across the UK – today. In the coming year we will receive grant applications for several million pounds. We hope to be able to provide funding in the region of £750,000 to independent researchers across the UK.



# Restricted Guarantee

## Special Appeal Projects



If we had the funds we could do so much more to help disabled children and their families. These are some of the projects we would like to develop over the next three years:

### 'Just Can't Wait' Equipment Service

Over 25% of applications for Newlife support are cases of a life-limiting (terminal) nature. These children 'just can't wait'; their needs are very urgent. Newlife provides equipment now to help these children but there are more children who usually need equipment for a limited time, than we have the ability to provide. In addition the nature of their situation means they need a fast service and when the equipment is no longer needed, to care for the family's emotions the equipment needs to be removed quickly and with care. The kind of delays that are endemic in the current statutory provision system means some children die before their equipment even arrives.

We propose a rapid response service where children get the right equipment fast and when equipment is no longer needed, it is reclaimed and refurbished and made available to help the next child in need. All of this needs to be done above all with sensitivity and compassion.

**Funding needed: £150,000**

### Development of the Intervention Service.

At the present time, just one member of staff covers all of the campaign, intervention and awareness work. The intervention work in particular is a very cost-effective project because it gets local statutory authorities paying for the equipment that they should be paying for allowing Newlife to provide for the surplus. Last year, intervention work leveraged almost £25,000 in a part time capacity.

In addition, we have also changed policy at local level getting the statutory bodies to accept their responsibility and remove restrictive or rationing practices that deprive children and families of their rights and services.

We could help more families in this way and work with more local statutory providers if we had more staff time and resources to achieve this.

**Funding needed: £25,000 Per Annum**

# Three

“Newlife’s grant gave us peace of mind to ensure the best treatment for our child. Thank you so much, we can keep our sanity. From the bottom of our hearts, thank you Newlife”

*Family Quote*



### Nurses and Professional Care

In the year 09/10 calls to the Nurse Helpline increased by 300% in the first half of the year. The nation’s financial climate, unemployment, the widening of Newlife’s remit to cover more disabilities, the PCT and Local Authority funding cutbacks, the closure of respite care services in some areas and reduction in funding at hospices resulting in less beds available for terminally ill children, is all taking its toll on families and their disabled children. Newlife Nurses are there ‘battling on the side of the family’ to help them in so many ways. But the phones ring out, as soon as they hang up one call, it rings again. We need to fund another part time Nurse and add a part time Social Worker to the team of professionals at Newlife to meet increasing demand.

*Funding needed: £30,000*

# Year Development Plan



# Financial Statement

## Over £2m raised 2008/2009

The Charity spent £2.5m over the same period, of which 84% was on charitable activities - most notably in the area of Nurse Services and Equipment Grants - where we funded 736 grants at a cost of just under £1m.

We continued to support and fund vital medical research with 16 new grants (startup and full) in the year of varying value totalling almost £700k.

Overall this has led to a decrease in the funds held by the charity to £4.1m. Of these funds 74% have been designated by the Charity's Trustees for specific charitable projects over the next year to eighteen months. In addition, plans after the year end have designated other available funds.

### Incoming resources

	2009	2008
Voluntary Income*	88,100	160,320
Internal Fundraising Activities*	251,062	314,774
Profit from Trading Company	1,384,708	1,342,584
Investment Income	303,863	381,295
Total Incoming Resources	2,027,733	2,198,973
<b>*Total Restricted Income</b>	<b>206,156</b>	<b>265,624</b>

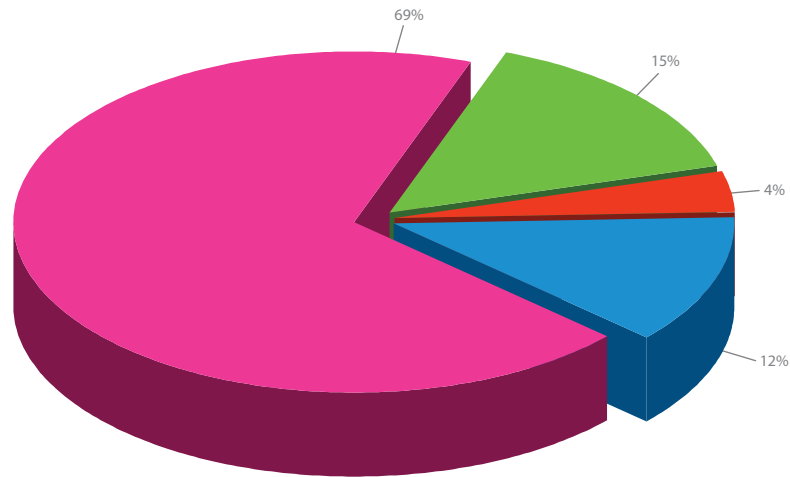
### Resources expended

	2009	2008
Charitable Aims	2,051,293	2,191,629
Cost of Generating Funds	368,180	215,722
Governance	33,511	32,191
Total Resources Expended	2,452,984	2,439,542
<b>Net outgoing resources before investment gains / losses</b>	<b>(425,252)</b>	<b>(240,569)</b>
Change in Value of Investments	(638,949)	(591,362)
Net movement in funds	(1,064,201)	(831,931)

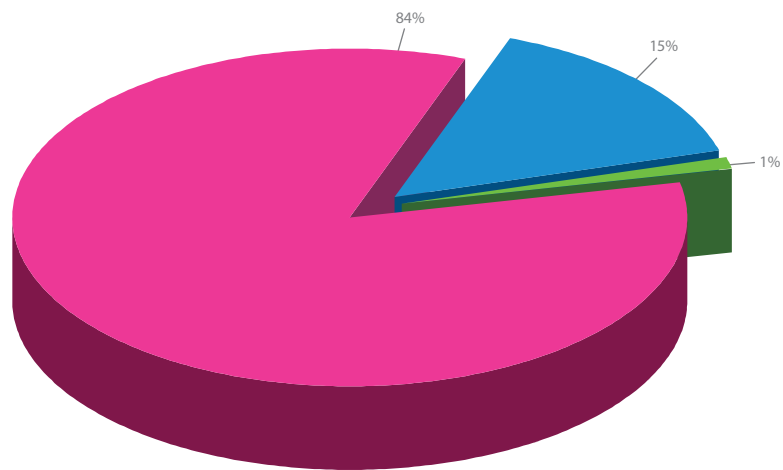
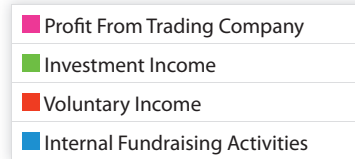
### Fund balances

	2009	2008
Restricted Funds	10,215	21,893
Designated Funds	2,064,081	2,330,556
Charitable Activity Reserve	996,304	1,310,449
Free Reserves	1,047,775	1,519,678
Fund Balances	4,118,375	5,182,576

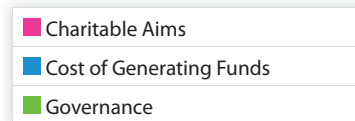




In 2008/09 we raised £2,027,733 - with almost 70% coming from our trading subsidiary.



Over the same period we spent £2,452,984 - with 84% going directly to our charitable activities.



“...Words are not enough to describe what the grant scheme has done for us. Newlife gave us the yes for the car seat within two hours of receiving the application!”

*Family Quote*

## Roll of Honour & Trustees



# Thank you...

During 2008/2009 Newlife Foundation had the kind support from the following Trusts and Foundations and companies.

### Trust Donors 1st April 08 - 31st March 09

Amanda Lee Charitable Trust  
Ammco Trust  
Baron Davenports Charity  
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Joseph Patrick Trust  
Yorkshire Building Society Charitable Foundation

### Corporate Donors 1st April 08 - 31st March 09

River Island  
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IDAHO Design  
Aurora Fashions Ltd  
Dermalogica (UK) Ltd  
Yorkshire Fairs Ltd  
Liquidlogic  
Gap  
Fluid Network Solutions Ltd

Newlife also benefited from donations of stock for re-sale from over 150 retailers and suppliers and from funds raised by our dedicated volunteers all over the UK. The staff and Trustees of Newlife Foundation and all of the children and families we serve are grateful for the generosity of all of these individuals, Trusts, companies and service societies.



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Mr. C. Lewis  
Mr. L. Lewis  
Professor M. Patton

#### Principal Officers

Mrs. S. Brown, OBE, FRSM, Chief Executive Officer  
Mr. S Morgan, Operations Manager  
Mrs. E Jackson, Finance Director  
Mrs. P Grant, Development Director  
Ms. Mary O'Donovan, National Appeal Director

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**Head Office:** Newlife Centre,  
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#### Medical And Scientific Advisory Panel

Professor Michael Patton (Chair and Medical Director)  
Dr. Lyn Chitty  
Professor David Dunger  
Dr. Victoria Murday  
Dr. Judith Rankin  
Professor Peter Scambler  
Professor Andrew Wilkie





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