

"ARC's support made an enormous difference to us"

Victoria's story

At our 20 week scan we were told that the baby was a little on the small side and referred for a more detailed scan at a specialist fetal medicine unit. That was when it all fell apart. The specialist sonographer listed all the problems she could see with our baby - there was a hole in the heart, the heart was on the wrong side of the body, the baby's fists were permanently clenched, her throat and stomach were unconnected...on and on and on.... I didn't take in the rest. All of these structural problems were symptoms of a severe chromosome disorder called Edwards syndrome. Our baby was very unlikely to survive the pregnancy and even if she did, and then managed to beat the odds to survive the labour, she was unlikely to live for more than a week. In the end, I couldn't face going through an indefinite number of days and weeks ahead not knowing exactly when our baby would die. The thought of people seeing my bump and asking me when my baby was due, or feeling her moving around but knowing she wouldn't make it, was too much. We decided, with broken hearts, to terminate the pregnancy. ARC's support made an enormous difference to us. Their advice helped us to prepare for the short few hours we would have with our daughter after she was born and make sure we made the absolute most of that precious time.



Looking Forward

Three aims for next year

- 1** To audit our support services to help inform our future plans.
- 2** To hold a successful 30th anniversary conference for healthcare professionals in March 2018.
- 3** To redevelop and extend our online support services.

Thank You

Your donations really do make a big difference. Without you we couldn't exist, so thank you to everyone who has donated to ARC this financial year.

Special thanks to Uniserve Holdings Ltd, The Goldsmiths' Company, Abbvie, Genesis Genetics, Illumina, The Scan Clinic, Premaitha Health, Natara, Diagnostic Ultrasound Services, Ariosa and Beard Mill Clinic.

ARC's national helpline

Want to talk? Call **020 7713 7486** or email us at info@arc-uk.org

Donate to ARC, we need your support

Help us ensure we can continue to support future parents, donate online to ARC at www.arc-uk.org/donate



345 City Road, London, EC1V 1LR

Admin **020 7713 7356**

Email info@arc-uk.org

Visit www.arc-uk.org

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Annual review designed by www.carrcreative.co.uk



ARC's impact

2016-2017 Annual Review

About ARC

1 We believe that every parent should have access to non-directive information and support through antenatal testing and its consequences.



1 chair

2 We seek to remain at the forefront of policy development and work in partnership with policy makers and healthcare professionals in order to achieve best care for parents.



1 treasurer

3 We believe that parents must be able to make choices based on their individual circumstances.



6 trustees

UK-wide support network of 25 volunteers who are trained by us to use their personal experience to offer support to others.



4.7 wte staff

Support to parents

6,300 anxious expectant parents and bereaved parents like Victoria used our helpline service

403 of these parents were newly bereaved

45 parents attended face-to-face meetings

2,200 parents used our forum

"I have found living with loss of this kind is turbulent and unpredictable. What isn't unpredictable though is ARC. It is constant, dependable and committed and there is no other organisation that supports parents in the same way. I am so grateful to have been able to access this support."

"I cannot ever really express my gratitude and thanks to you for your unwavering support during what has been the most horrendous time of my life. You have had calm patience with me at my most neurotic and that to me has been the thing that has pulled me through."

Over 100,000 website visitors - 15% increase on last year



Working with healthcare professionals to improve care

Over 900 healthcare professionals trained across the UK - 29% increase from last year.

Study days held in London, Shrewsbury and Kent.

Workshops for healthcare professionals held in Swansea, London, Essex and Wishaw.

Students trained at Kings College London, Queen's University Belfast and the Universities of Bedfordshire, East Anglia, West London, Bournemouth and Swansea.

Guest speaker at professional conferences in Liverpool, London, Birmingham and Stockholm.

"I was so happy that I attended this study day. This has empowered me in the way I deliver care to clients especially in my new role as a screening midwife."

"Fantastic Day. Extremely informative and so helpful. Loved sharing best practice experiences of other participants. Looking forward to the next day!"

Working with policy makers, researchers and the media

ARC continued to be represented on the UK National Screening Committee (UKNSC) and the NHS Fetal Anomaly Screening Programme Advisory Group to advise on matters of antenatal screening policy. ARC's director chaired a four country working group aiming to agree a process for the development of information for the public and professionals across all screening programmes.

ARC worked closely with the Fetal Anomaly Screening Programme on plans for the implementation of non-invasive prenatal testing (NIPT) into the NHS in 2018.

Financials

Income

| | | |
|-----------------------|---------|----------------------------------|
| Total | 208,372 | <div style="width: 100%;"></div> |
| Donations | 59,784 | <div style="width: 28%;"></div> |
| Grants | 36,000 | <div style="width: 17%;"></div> |
| Fundraising | 65,643 | <div style="width: 31%;"></div> |
| Professional training | 35,535 | <div style="width: 17%;"></div> |
| Publications | 5,872 | <div style="width: 3%;"></div> |
| Other | 5,538 | <div style="width: 3%;"></div> |

Expenditure

| | | |
|-------------------------|---------|----------------------------------|
| Total | 234,164 | <div style="width: 100%;"></div> |
| Governance | 35,099 | <div style="width: 15%;"></div> |
| Fundraising costs | 14,230 | <div style="width: 6%;"></div> |
| Support and information | 140,521 | <div style="width: 60%;"></div> |
| Professional education | 44,314 | <div style="width: 19%;"></div> |

This financial year left ARC with a deficit of £25,814.

If you value the services offered by ARC and wish to donate visit www.arc-uk.org/donate



The screening in October 2016 of the BBC2 programme 'A world without Down's Syndrome' fronted by actress Sally Phillips, prompted significant media interest. In the wake of its broadcast, ARC's director appeared on and was featured in:

BBC Breakfast TV • C5 News • BBC R4 Moral Maze • BBC R2 • BBC R5 Drive • LBC • BBC Radio Cambridge • BBC Radio Oxford • BBC Radio Wales • BBC Radio Birmingham • BBC Radio Berkshire • BBC Radio Ulster • Observer • Daily Mail • Huffington Post • Nursing Standard