

Charity/Support Contact List

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1. UK HEART CHARITIES

	Name	phone	Website	email
NATIONAL HEART CHARITIES	HeartLine Association Forum for parents to connect, arranging caravan holidays, wetsuits, a summer event, publish a series of books.	033 00 22 44 66	http://www.heartline.org.uk/	admin@heartline.org.uk
	Little Hearts Matter Offers support for children with only half a heart, Pulmonary Atresia, Tricuspid Atresia, Hypoplastic Left Heart Syndrome (HLHS) or Double Inlet or Outlet Ventricle (Univentricular Heart)	0121 455 8982	http://www.lhm.org.uk/	info@lhm.org.uk
	Lagans Foundation (Young children and feeding problems)	01204 468300	http://www.lagans.org.uk/	info@lagans.org.uk
LONDON	The Brompton Fountain Supporting families treated Royal Brompton and Harefield NHS Trust.	03300 22 92 91	http://www.thebromptonfountain.org.uk	
	Evelina Children's Heart Organisation Support for families of heart children treated at the Evelina Children's Hospital.	07715 208077	www.echo-evelina.org.uk	
SOUTH WEST ENGLAND	South West Children's Heart Circle Supporting, counseling and visiting for families with heart children South West of England and Wales.	08701252307	www.heartcircle.org/	
OXFORDSHIRE	Young Hearts Supporting children Oxfordshire, Gloucestershire, Wiltshire, Berkshire, Buckinghamshire & Northants	N/A	http://younghearts.org.uk/	support@younghearts.co.uk
CENTRAL ENGLAND/BIRMINGHAM	Young at Heart Supporting families of children treated at the Cardiac Unit, Birmingham Children's Hospital.	0121 357 8200	http://www.youngatheart.org.uk/	support@youngatheart.org.uk contactus@youngatheart.org.uk

	Heartlink Supporting families from the East Midlands		http://www.heartlink-glenfield.org.uk/	
	Children's Heart Association Support to parents and families, help purchase specialized equipment.	01706 221988	http://heartchild.info/web/	
SCOTLAND	The Scottish Association for Children with Heart Disorders (SACHD) Support in Scotland (Aberdeen, Banff & Buchan, Edinburgh, Glasgow, Dumfries and Tayside)	N/A	http://www.youngheart.info/contact	N/A
IRELAND/NORTHERN IRELAND	Heart Children Ireland	1850 217 017 or alternatively (00 353 1) 8740990 (Within Republic of Ireland)	http://www.heartchildren.ie/	heartchildren@eircom.net
	Heartbeat Northern Ireland	+44(0)75 8416 4815	www.heartbeatni.com	info@heartbeatni.com

2. INTERNATIONAL HEART ORGANIZATIONS (ECHDO members)

Country	Name	webiste	email	phone
Austria	Herzkinder Österreich	www.herzkinder.at	office@herzkinder.at a.lang@herzkinder.at	+43 (0) 664 432 56 56
Belgium	Hartekinderen	www.hartekinderen.be	info@hartekinderen.be	N/A
Bulgaria	Childs Heart	www.childsheart.eu	as_childs_heart@yahoo.com	+ 359 2 953 28 66
Croatia	Big heart little heart	www.velikosrce-malomsrce.hr	N/A	N/A
Cyprus	Pediheart	www.pediheart.org.cy	pediheart@cytanet.com.cy	+2231 51 46 96
Czech Republic	Srdickari	www.srdickari.cz	info@srdickari.cz	+420 603 262 405
Denmark	Hjerteforeningens Børneklub	www.hjertebarn.dk	formand@hjertebarn.dk	N/A
Estonia	MTÜ Südamelaste Tugiühing	www.sydamelaps.ee	info@sydamelaps.ee	N/A
Finland	Sydänlapset ja – aikuiset ry	www.sydanlapsetjaaikuiset.fi	katja.laine@sydanlapsetjaaikuiset.fi	+358 (0)9 7527 5275
France	Association Nationale Des Cardiaques Congenitaux (ANCC)	www.ancc.asso.fr	masseronmarie@orange.fr	N/A
Germany	Bundesverband Herzranke Kinder e.V.	www.bvhk.de	bvhk-aachen@t-online.de	+49 (0)241-91 23 32
Northern Ireland	Heartbeat Northern Ireland	www.heartbeatni.com	info@heartbeatni.com	N/A
Northern Ireland	Children's Heartbeat Trust (NI)	www.childrensheartbeattrust.org	info@childrensheartbeattrust.org	N/A
GB	The Somerville Foundation	www.thesf.org.uk	N/A	0800 854 759
Greece	Kardiapaidiou	www.kardiapaidiou.gr	info@kardiapaidiou.gr Or kardiap@yahoo.gr	+30-2103218488 or +30-2103253876

Iceland	Neistinn	www.neistinn.is	gudrun@hjartaheill.is or neistinn@neistinn.is	N/A
Ireland	Heart Children	www.heartchildren.ie	heartchildren@eircom.net	+353-1-8740990
Italy	Aicca	www.aicca.eu	edward.callus@gmail.com or emilia.guadri@grupposandonato.it	+39 02 5277 4677
Italy	Kinderherz	www.kinderherz.it	info@kinderherz.it	+39 366 36 36 030
Lithuania	Vaikosirdis	www.vaikosirdis.lt	daiva@mazojisirdede.lt or kostas@vaikosirdis.lt	+37 445 471 65
Luxembourg	Luxcordis	www.luxcordis.org	info@luxcordis.org	0352-621-656-944
Netherlands	Patiëntenvereniging Aangeboren Hartafwijkingen (PAH)	www.aangeborenhartafwijking.nl	info@aangeborenhartafwijking.nl	+31 880063600
Norway	FFHB	www.ffhb.no	marte@ffhb.no	004723058000
Poland	Fundusz Serce Dziecka	www.sercedziecka.org.pl	fundacja@sercedziecka.org.pl	0048 / 601-228-073
Romania	Acmim	http://www.acmim.ro	contact@acmim.ro	N/A
Romania	Protcard	www.protcard.org	contact@protcard.org	+40 21 3114938
Slovenia	Zasrce	www.zasrce.si	drustvo.zasrce@siol.net	N/A
Spain	Aacic	www.aacic.org	info@aacic.org	+ 93 458 66 53
Spain	Menudos Corazones Foundation	www.menudoscorazones.org	informacion@menudoscorazones.org	+34 -91 373 67 46 or +34 -91 386 61 22
Sweden	Hjärtebarnsföreningen	www.hjartebarn.org or www.hjartebarnsfonden.org	peter.nordqvist@hjartebarn.org	+46-(0)8442-4650 / +46-(0)525 325 41
Switzerland	EVHK	www.evkh.ch	N/A	N/A

3. SPECIFIC CONDITIONS

Name	Phone	Website	Email
Arrhythmia Alliance	+44 (0)1789450787	http://www.heartrhythmcharity.org.uk/	info@heartrhythmcharity.org.uk
Barth Syndrome Trust	+44 (0) 1794 518 785	http://www.barthysyndrome.org.uk/	http://www.barthysyndrome.org.uk/GetinTouch.php
Charlie Jones Foundation (Deals with	07977 335 002	http://www.charliejonesfoundation.org.uk/	info@charliejonesfoundation.org.uk

Hypoplastic Left Heart Syndrome)			
CRY Cardiac Risk in the Young	01737 363 222	http://www.c-r-y.org.uk/	cry@c-r-y.org.uk
Cardiomyopathy Association (CMA)	01494 791224 or freephone: 08000181024	http://www.cardiomyopathy.org/	http://www.cardiomyopathy.org/contact-us-by-email.html
Downs Heart Group	0844 288 4800	www.dhg.org.uk	info@dhg.org.uk
Ebsteins	N/A	http://www.ebsteins.org/	N/A
Little Hearts Matter Supporting (helpline) parents of children with single ventricle heart condition, such as Hypoplastic Left Heart Syndrome, Tricuspid Atresia, Double Inlet Ventricle or Pulmonary Atresia (+ Antenatal, bereavement etc).	0121 455 8982 from 4.30 pm – 10 pm Mon-Fri and at weekends.	http://www.lhm.org.uk	info@lhm.org.uk
Max Appeal DiGeorge syndrome, VCFS and 22q11.2 deletion.	0300 999 2211	www.maxappeal.org.uk	info@maxappeal.org.uk
SADS Sudden Arrhythmic Death Syndrome	N/A	http://www.sads.org.uk/	N/A

4. ANTENATAL

Name	website	email	phone
ARC Antenatal screening and its consequences	http://www.arc-uk.org/	info@arc-uk.org	0845 077 2290 or 0207 713 7486 via mobile

5. FAMILY SUPPORT

Name	website	email	phone
Grandparents Association	http://www.grandparents-association.org.uk/	wb@grandparents-association.org.uk	0845 4349585
Siblings (For siblings of disabled children)	http://www.sibs.org.uk/	info@sibs.org.uk	01535 645453
Medic Alert	http://www.medicalert.org.uk/index.php	info@medicalert.org.uk	01908 951045
Carers Trust	http://www.carers.org/	info@carers.org	0844 800 4361
Carers Direct Helpline (NHS)	http://www.nhs.uk/carersdirect/carerslives/updates/pages/carersdirecthelpline.aspx	N/A	0300 123 1053
Independent Parental Special Education Advice	http://www.ipsea.org.uk/	0800 018 4016	
The National Parent Partnership Network (NPPN)	http://www.parentpartnership.org.uk/	0207 843 6058	

6. SPECIAL EDUCATION

IPSEA legally based advice to families who have children with special educational needs	http://www.ipsea.org.uk/	N/A	0800 018 4016
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7. WISH CHARITIES

Name	Website	Notes
Over the Wall (Also sibling and family camps)	http://www.otw.org.uk/	8-17 years
Make a wish	http://www.make-a-wish.org.uk/	For seriously ill children only
Winston's wish	http://www.winstonswish.org.uk/	Bereaved children
Honeypot holidays	http://www.honeypot.org.uk/	Holiday cottages

8. SOCIAL CARE AND DISABILITY ALLOWANCE

Name	Website	Notes
Carers and disability benefits	https://www.gov.uk/browse/benefits/disability	
Disability Living Allowance	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/307913/dla1a_child.pdf	
Carer's Allowance	https://www.gov.uk/carers-allowance	
Contact a family (charity supporting families with disabled children)	http://www.cafamily.org.uk/	Advice on benefits/rights, aids with equipment, fuel bills...

9. GRANT APPLICATION

Medical equipment, wheel chairs: £ 100-6000	Variety
For GUCH (16-24) Non specified	Somerville Foundation
Grants, support for terminally ill children	Rainbow Trust
Research	Heart Research

10.INTERNATIONAL SUPPORT

Name	Website	Phone
Helping Children with Heart Defects Abroad	http://www.childrensheart.org.uk/	+44 208 241 6749
Provide children suffering from life-threatening heart disease with the corrective surgery	http://www.chainofhope.org/	+44 020 7351 1978
Helping heart children worldwide	http://www.childrensheartlink.org/	(952) 928-4860
Provide children suffering from life-threatening heart disease with the corrective surgery	http://babyheart.org/	Tel - (877) 869-4243

11. Counseling

Name	Website	Phone
Anxiety UK Support, help and information for those with anxiety disorders (including post-traumatic stress disorder).	www.anxietyuk.org.uk	
Somerville Foundation The Somerville Foundation is a national charity supporting adults with Congenital Heart Disease and they have a wide range of emotional and mental health resources here . Their mental health support worker, Anne Crump is able to talk through an emotional or mental health issue and you can contact her on anne@thesf.org.uk or call the Somerville Foundation Patient Helpline on 0800854759 .	http://www.thesf.org.uk/	Phone: 0800854759

12. PALS - Patient Advice

Name	Website	Phone
PALS Patient advice and liaison services	http://www.nhs.uk/chq/Pages/1082.aspx?CategoryID=68	N/A

13. BEREAVEMENT

Name	Website	Email	Phone
The Child Bereavement Charity	http://www.childbereavement.org.uk/		01494 446 648
Child Death Helpline	http://www.childdeathhelpline.org.uk/		01494 446 648
Cruse Bereavement Care	http://www.cruse.org.uk/		0844 477 9400
The Compassionate Friends For bereaved parents and their families.	http://www.tcf.org.uk/		2304

14. HOSPICES

Name	Website	Phone
Togetherforshortlives	http://www.togetherforshortlives.org.uk/	0808 8088 100