

# Support Groups & Associations

Now that your child has a stoma you may feel you want to talk to someone else in the same situation, or even swap tips with them.

Following is a list of support groups you may like to contact for help and advice.

## Action for Sick Children

Is the UK's leading children's healthcare charity, specially formed to ensure that sick children always receive the highest standard of care possible.

#### Address

3 The Boulevard, Ascot Road, Watford, WD18 8AG

Telephone 01923 361 500

Website www.actionforsickchildren.org.uk

## Association for Spina Bifida and Hydrocephalus (ASBAH)

Address ASBAH House, 42 Park Road, Peterborough, PE1 2UQ

Helpline 0845 4507 755

Fax 01733-555985

E-mail helpline@asbah.org

Website www.asbah.org



## Contact a Family for Families with Disabled Children

Provides advice, information and support to all parents of all disabled children. Parents are able to get in touch with other families, locally and nationally.

## Address 209-211 City Road, London, E1V 1JN

Telephone 0808 808 3555 or 020 7608 8700

E-mail helpline@cafamily.org.uk

Website www.cafamily.org.uk

## Crohn's in Childhood Research Association (CICRA)

#### Address

Parkgate House, 356 West Barnes Lane, Motspur Park, Surrey KT3 6NB

Telephone 020 8949 6209

Website www.cicra.org

E-mail support@circ.org

#### **Down's Syndrome Association**

#### Address

The Langdown Centre, 2a Langdown Park, Teddington, TW11 9PS

#### Telephone 0845 230 0372

Monday – Friday, 10am to 4pm

Website www.downs-syndrome.org.uk

#### **The Family Fund**

Is a registered charity which provides grant and assistance to families with severely disabled children, ensuring they have choices and opportunities to enjoy life.

E-mail info@familyfund.org.uk

Website www.familyfundtrust.org.uk

#### **Disability Living Allowance**

Dedicated telephone line for advice and completion re claims.

#### Address

4 Alpha Court, Monks Cross Drive, York, YO32 9WN

Telephone 0845 130 4542 or 01904 621 115

## Hirschsprungs and Motility Disorders Support Network (HMDSN)

Is an organisation that makes it possible for people and families, whose children have Hirschsprung Disease and other gastrointestinal motility disorders to support each other.

#### Address

The Willows, Forest Road, Leicestershire, LE19 3LD

Telephone 07935 787 776

Website www.hirschsprung.info

## National Association of Special Educational Needs (NASEN)

Helpline 0207 258 3222. A fee is charged for a key to gain access to disabled toilets, if not available from local council authority.

#### Address

Nasen House, 4/5 Amber Business Village, Amber Close, Amington, Tamworth , Staffordshire, B77 4RP

Telephone 01827 311500

Email welcome@nasen.org.uk

Website www.nasen.org.uk

## National Key Scheme for Disabled Toilets (RADAR)

A fee is charged for a key to gain access to disabled toilets, if not available from local council authority.

#### Address

12, City Forum, 250 City Road, London, EC1V 8AF

Telephone 0207 250 3222

Email radar@radar.org.uk

Website www.radar.org.uk

## **National Kidney Foundation**

Address

The Point, Coach Road, Shire Oaks, Worksop, Nottinghamshire, S81 8BW

Telephone 0845 6010209

E-mail nkf@kidney.org.uk

Website www.kidney.org.uk

## The lleostomy and Internal Pouch Support Group (ia)

The primary aim is to help people who have undergone surgery which involves the removal of their colon (colectomy) and the creation of either an ileostomy or an ileonal pouch.

#### Address

National Office, Peverill House, 1-5 Mill Road, Ballycare, County Antrium, BT39 9DR

## Telephone

0289 332 4606

Fax 028 9334 4043

E-mail info@iasupport.org

Website www.iasupport.org

## **Urostomy Association (UA)**

Address Central office, 18 Foxglove Avenue, Uttoxeter, Stafforshire, ST14 8UN

Telephone 0845 241 2159

E-mail Secretary.ua@classmail.co.uk

Website www.urostomyassociation.org.uk

#### **TOFS Support Group**

Dedicated to providing emotional support to families of children born with tracheo-oesophageal fistula, oesophageal atresia and associated conditions.

#### Address

St. George's Centre, 91 Victoria Road, Netherfield, Nottingham, NG4 2NN

Telephone 0115 961 3092

E-mail info@tofs.org.uk

Website www.tofs.org.uk

VACTERL Association Support Group Dedicated to helping families affected by VACTERL/VATER Association based in the UK.

Telephone 01752 482 568

E-mail General information info@vacterl-association.org.uk Help and support support@vacterl-association.org.uk

Website www.vacterl-association.org.uk

## ERIC – Education Resource for Improving Childhood Continence

This website provides information and support on childhood bedwetting, daytime wetting, constipation and soiling to children, young people, parents and professionals.

## Address

36 Old School House, Britannia Road Kingswood, Bristol BS15 8DB

#### Telephone

0845 370 8008 (Monday – Friday, 10am – 4pm)

E-mail info@eric.org.uk

Website www.eric.org.uk

#### **Breakaway Visits**

Breakaway Visits offers residential adventure activity breaks for young people between 4-18 years with bowel and/or bladder diversions and dysfunctions and their families. Breakaway offers

the chance for families and young people to meet, talk and share their experiences in a relaxed and friendly environment. The main aim of Breakaway though, is to have fun!

## Website

www.breakaway-visit.co.uk

## PromoCon – Promoting Continence and Product Awareness

PromoCon provides a national service to improve the life for all people suffering with bladder or bowel problems by offering product information, advice and practical solutions to both professionals and the general public.

#### Address

PromoCon, Redbank House, 4 St Chads Street, Cheetham, Manchester, M8 8QA

#### Telephone

0161 834 2001 (Monday - Friday 10am to 3pm)

E-mail Promocon@disabledliving.co.uk

Website www.promocon.co.uk



#### Network 81

Network 81 is a national network of parents working towards properly resourced, inclusive education for children with special education needs.

#### Address

1-7 Woodfield Terrace, Stansted, Essex, CM24 8AJ

Telephone 0845 077 4055

E-mail info@network81.org

Website www.network81.org

## Smille's People – National Association for Colitis & Crohn's Disease (NACC)

Smilie's people is a support group for children, young people and their families for information and support about Crohn's and Ulcerative Colitis. It is part of NACC.

#### Address

4 Beaumont House,Sutton Road, St Albans, Herts ALI 5HH

Telephone 0845 1302233

#### Website

www.nacc.org.uk

#### Spinal Injuries Association

#### Address

SIA, 2 Trueman Place, Oldbrook, Milton Keynes, MK6 2HH

Telephone 0800 980 0501 or 0845 678 6633

Fax 0845 0780 6911

E-mail sia@spinal.co.uk

Website www.spinal.co.uk

#### The Colostomy Association

Is a national registered charity, which represents the interest of people with a colostomy, providing support, reassurance and practical help.

Address 2 London Court, East street, Reading RG1 4QL

Telephone 0800 328 4257

E-mail cass@colostomyassociation.org.uk

Website www.colostomyassociation.org.uk

This leaflet has been produced by ConvaTec, working in conjunction with Specialist Nurses from the Paediatric Stoma Nurse Group (PSNG). ConvaTec is one of the world's leaders in making and supplying stoma equipment. ©2010 Copyright in the content resides with the members of the Paediatric Stoma Nurse Group (PSNG) as at date of production, ©2010 Copyright in the layout and other supporting material resides with ConvaTec Inc. AP-010389-GB\_PAED34



