

**FAMILY SUPPORT WORKER  
RECRUITMENT PACK  
JAN 2019**

**you can make the difference  
for children and young people  
with inflammatory bowel disease**

**cicra** 

better lives for children with crohns and colitis



We are the specialist charity for children and young people affected by crohns and colitis.

We **lead research** into better treatments, **support children and families** with relevant information, work with health professionals to **improve care** and **give children a voice** to increase public understanding of Crohn's and colitis.

We believe that all children deserve **a childhood unlimited by inflammatory bowel disease.**

Pat Shaw House  
13-19 Ventnor Road  
Sutton  
SM2 6AQ

020 8949 6209  
recruitment@cicra.org

[www.cicra.org](http://www.cicra.org)

Find us on social media  
@CICRAcharity

CICRA is the operating name of Crohns In Childhood Research Association, a registered charity in England and Wales (number 278212) and Scotland (SC040700)

*Photographs by Vicki Sharp Photography*

In 1978, a small group of parents with young children being treated for Crohn's by Professor John Walker-Smith at St. Bartholomew's Hospital, London, desperately wanted to find out why their children had been affected by a condition which, until then, had only been seen in adults. Steroids and surgery were the only treatments available, so the only practical way they could help was by raising funds for research.

There are now 27 very busy specialist centres in the UK, and the incidence of inflammatory bowel disease (IBD) in children is still increasing – doubling over the past 20 years. Many are now diagnosed as babies or toddlers. As a comparatively small national charity, we are able to give personal support and understanding to all members of the family. We have now helped thousands of families, but there are many more still in need of support.

Hearing that your child has Crohn's disease or Ulcerative colitis is exactly the same for families today as it was in the seventies: initial shock, perhaps relief at somebody putting a name to it, but then fear for the future. Our aim, until we find a cure, is for children to experience all the usual childhood activities, education and social life unimpeded by IBD.

This new role of a Family Support Worker is essential to our objective of helping all families with a child affected by Crohn's or colitis. Your professional experience will help more children and families in their time of desperate need. You can help ensure these families get the support that makes such a difference and that children can have a childhood unlimited by IBD.

You will be joining the charity at a crucial time in our history – with lots of new information resources, a much improved website, renewed IBD Standards, growth in our family information days and a continuing focus on research and the training of paediatric gastroenterologists. We are respected and supported by health professionals right across the UK, who have been enthusiastic about this new role and the opportunity it presents for us to make sure every child with Crohn's, colitis and any form of IBD and their family has somewhere – and someone – to turn to.

I hope you will give this opportunity serious consideration and I really look forward to hearing from you. Please do email me if you would like to arrange a time to get more information about the role and why it will play such an important role for the charity and all of those we exist to help.

**Nick Posford, Chief Executive, CICRA**



## introduction

CICRA is the specialist, national charity for children and young people with Crohn's disease, Ulcerative colitis and all forms of inflammatory bowel disease (IBD).

This is a really exciting time for CICRA. In the past year we have started work on an ambitious ten-year plan to give us as good as a cure – with four goals driving our work:

- advances due to research mean children are given more personalised treatments, with limited side effects
- all children and families get the information they need, when they need it, and in the format that works for them
- all children with IBD and their families know where to turn for support and get help straight away
- the needs of children with IBD are always understood and supported, in healthcare, education and society

As a passionate champion of the voice of children and young people with IBD, we are growing the information and support we offer for different stages of childhood. Thanks to Global's Make Some Noise, we are excited to be recruiting for this important new role at the heart of our work supporting children with IBD and their families.

## how Crohn's and colitis affect childhood

Inflammatory bowel disease (IBD) is a life-long condition, which is very unpredictable and can have frequent flares and relapses. When IBD is active, children and young people need regular and prolonged access to toilets, as a common, embarrassing and distressing symptom is frequent diarrhoea. However, the impact of the disease is much wider and many children suffer with fatigue and pain, fever, nausea, loss of appetite, loss of concentration and lack of energy. Some children also live with pain and inflammation of the skin, joints and eyes. Some children may require surgery to the area around the bottom.

Many children with IBD are small for their age, making them appear younger than their classmates which can make them a target for bullies. Combined with the strain of living with their condition, this can make them become withdrawn, anxious and depressed. Relapses can be particularly difficult to deal with emotionally. Children with IBD require treatment with medicines. Steroids are a common treatment and have distressing side effects, which affect a child's appearance (e.g. weight gain, puffy face and acne), mood and behaviour. Others suppress the immune system, leaving children more vulnerable to normal infectious diseases like chicken pox. Some children will also have a nutritional feed via a nasogastric tube. Children with IBD will need to visit hospital for regular routine appointments and for invasive investigations, including endoscopy. Some children will require surgery to remove diseased sections of the bowel and some may need a stoma.





## what we are doing to make things better

Children and their families tell us that CICRA is so important because we provide trusted information and a reliable source of support that many describe as a lifeline. We are a small charity dedicated to helping them live as normal a life as possible. To stop IBD impacting children, we are working hard on many fronts:

### **information to give them knowledge and power over their condition...**

Through our website and information booklets, we inform them about different aspects of IBD from psychological issues to treatments to diet and nutrition. We provide information to schools and teachers, we help increase the knowledge of general paediatricians, and we reassure children with straightforward, easy to understand insights into all aspects of Crohn's and colitis.

### **research for better treatments and to find a cure...**

We advance knowledge of childhood IBD by supporting high quality, peer-reviewed medical research which has led to new treatments being taken forward for clinical trials. Our research programme over 40 years has helped train many specialists and led to better understanding of what goes on in our bowels. Current research is looking at how treatments could be personalised to individual patients, avoiding the need to try different treatments in the search for the one that works for a child or young person with IBD.

### **support to help them live with the disease...**

We give children and families the opportunity to spend time with others in similar situations, and share their experiences of living with IBD. Growing up is hard enough, without having each and every rite of passage ruined by a chronic disease you can't talk to anyone about. Being able to hang out with other people who know what they are going through is the one thing they all want – to know they are not alone, to feel they are normal kids.

### **a voice to say what matters to them...**

Children inspire our work, as they approach their disease with maturity and grace despite knowing they will have to deal with it for the rest of their lives. We give them a voice in all the areas that affect their health and wellbeing. From a seat at the table of medical professional associations to conferences on paediatric IBD to telling the public and their friends what life is really like with IBD.

We have been supporting children with Crohn's and colitis, and their families, for over forty years. Children and families tell us that the impact of IBD on childhood is their greatest concern. So, we want to counter the impact of Crohn's and colitis on educational achievement, and physical and emotional development, to give children back their childhood and help them transition into adult life without the frustrations and complications they currently might face.

## **giving children with IBD their childhood back** increasing emotional and practical support for children with crohns and colitis, and their families

This role delivers a step change in CICRA's support services, in response to feedback from children and families in our 2017 survey. The core of a wider project is our first full time Family Support Worker who will deliver direct support to children and families and manage the development and delivery of additional help and advice. The aim is to ensure children and families are getting the support they need, when they need it and in the format they want. Patient first, patient focused.

Using a variety of methods from face to face, group sessions, digital and telephone, this role and the wider project will provide essential emotional and practical support for children with crohns and colitis, and their families. It will help them come to terms with the diagnosis of a lifelong condition, and how to lead as normal a life as possible. The support will provide children, parents and siblings with ways to deal with the emotional and practical difficulties that come from inflammatory bowel disease and help them develop resilience and confidence to overcome any negative social attitudes in education and their community.





In our 2017 survey of 150 families across the UK, both children with IBD and their parents expressed universal, strong support for:

- increasing the understanding of schools, friends and society
- psychological support
- remission and cure

In 2018, we have developed new information for teachers at primary and secondary schools. Our research programme is focused on finding better treatments to keep children in remission until we find a cure. However, both of these are long term issues that will take time and a large effort to fully overcome. In the meantime, it is essential that support for children and their families is increased.

A diagnosis of IBD is a knock-out punch for children and families because it impacts their lives in so many ways – the physical aspects intersect with social taboos and confidence. Growth and development can be delayed at a crucial time, long periods of hospital stays and fatigue can be so overwhelming, they miss large chunks of school. Often a parent has to give up work because of caring responsibilities and repeat medical appointments. All of these combine to make inflammatory bowel disease a complex, debilitating and exhausting illness to deal with.

## about this role

This role of a Family Support Worker will help children and their families build emotional and mental resilience and strength so they can cope with a lifelong illness. Through the practical advice they receive, we hope the adverse impact of IBD will reduce to more manageable levels and give the children a chance of having their childhood back.

This role will have a dual focus of providing direct support to children and families (face to face at our popular meetings and through telephone, email and online) and helping to develop our wider support programme to support the needs of children and families. In particular, this role will:

- provide support to children, parents and siblings
- facilitate sessions at our Family Information Days
- increase support available through our website and helpline
- develop and increase our emotional and practical information
- support the development of our network of support groups

The funding from Global's Make Some Noise will also support:

***psychological issues information***: a range of expert authored information for our new website and available as downloads or in printed format

***support group network***: a network of peer support, based on hospitals where families have expressed a desire to meet others

***discussions at Family Information Days***: identifying techniques, approaches and services that can help children, parents and siblings

***digital sessions***: a series of live, regular sessions using youtube, facebook and twitter, in order to engage with many children and families

***helpline improvements***: training to help all staff be more effective when someone calls, and recruiting suitable volunteers to peer support others.

### what might your week involve?

Your working week might include time spent talking with parents of newly diagnosed children about IBD and how it has impacted their family and what they can do to help their child; talking through the information and support CICRA can offer to health professionals who want to help their paediatric patients; preparing for and delivering a half day workshop for some teenagers affected by IBD who are trying to build their confidence; discussing with CICRA colleagues the feedback given by families on our work; and helping to develop a new piece of information on an aspect of IBD. Your week will be varied and will require you to have drive and enthusiasm and an ability to build rapport with young people and parents.



## about the funding

This role has initially been made possible because of the support of Global's Make Some Noise, who have confirmed funding for the first year of the role and we are hopeful will confirm in April to fund a second year. We expect the role to prove popular with children and families, and the charity's intention is that – subject to satisfactory outcomes – the role will then continue to be funded as a core part of CICRA's support for young people with IBD. Although funding is only secured for *one year* at time of writing, as is common in charities, we hope to secure further funding and for the role to become permanent due to popular demand and evidence of positive impact.

## about the location

This role is offered as a home-based role with regular visits to the CICRA office in Sutton for team meetings and 1:1s with the CEO. Travel will also be required in order to deliver workshops or facilitate sessions at CICRA family days. We will provide all necessary equipment and pay any travel expenses in line with our expenses policy.

## about you

You will have experience of working with children and families, in health, education or community settings.

You will be able to organise your own workload and demonstrate initiative.

You will be able to deal tactfully with potential conflict.

You will be capable of accurate reporting and the communication of sometimes complex information to a variety of audiences.

You will be passionate about maximising a child's life chances.

You will care.

## about Global's Make Some Noise

Global's Make Some Noise is a national charity that funds and empowers projects, helping disadvantaged children, young people and their families, as close to home as possible.

They fund vital equipment and life-changing services to help children and young people through challenging times, including therapy, counselling, nursing and support groups.

They help bring to life a new project that's desperately needed like this role for CICRA or help other charities continue running the only service of its type in the UK.

Global's Make Some Noise gives a voice to small charities as they struggle to get heard. They are supported by Global, home of some of the UK's biggest radio brands including Heart, Capital, Classic FM, Smooth, LBC, Radio X, Capital XTRA and Gold. Along with experts from Global, they train the charities in marketing, digital and media, to boost their skills and build sustainability.

### Global's Make Some Noise putting CICRA in the spotlight

We want to make lots of noise about CICRA because of the support it provides to children like Mansi, who is affected by Crohn's Disease. She said:

"I was put on steroids, they gave me severe puffiness from the neck up. I was in primary school at the time and because I have always been quite skinny people asked me why I had gained so much weight in such little time. I got bullied, because of this I got anxiety and post-traumatic stress disorder. I felt sad all the time.

When I first came to CICRA I felt that there were other people in the same boat as me which helped me open up a bit more. Last year I was in Year 7 and I struggled to talk about Crohn's, this year I've been able to open up more about it with my friends at school."

Global's Make Some Noise is supporting CICRA to deliver a new project that will provide support to children to help them deal with the impact of Crohn's and Colitis. This project aims to help even more children have the best chance of enjoying childhood, despite their condition.



Staff Only

FIRE EXIT

## our impact

CICRA was the first IBD charity in the UK and our research had national impact from the start by giving young qualified doctors the opportunity to specialise in paediatric gastroenterology, so that there would be expert help for children with crohns and colitis.

Over time, as more children were diagnosed, we increased our support and information for families with a child affected by IBD and we have supported around 10,000 families to cope with their diagnosis and feel more positive about managing their condition.

We have invested over £5 million on research in the UK, leading to new treatments and specialised training in gastroenterology for 25 paediatricians, including many at the leading centres caring for children with IBD. Today, more children with Crohn's or colitis can see a childhood IBD specialist, because of our incredible supporters.

CICRA is a founding member of IBD UK and a member of the Association of Medical Research Charities. We work closely with the British Society of Paediatric Gastroenterology, Hepatology and Nutrition, and are helping to update the IBD Standards.

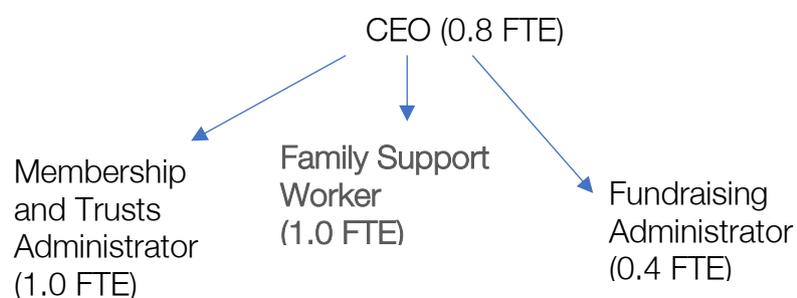
CICRA provides children and their families with:

- expert information on Crohn's, colitis, IBD unclassified, oral Crohn's and very early onset IBD
- understanding & support for the whole family including parents, carers and siblings
- *the insider* newsletter produced twice a year and sent free of charge to families
- easy to understand booklets & leaflets for parents, teachers & young people
- help with the transition from child to adult health services
- 'can't wait' cards issued FREE of charge to help children explain their condition when in urgent need of toilet facilities, and RADAR keys
- epals scheme for children & young people to chat and support each other by email
- parents in contact, for parents to provide practical support to each other
- regular IBD family information and support days across the UK
- information on travel insurance



## our team

We are a small but very dedicated team, and we place great importance on the charity being friendly and welcoming. Our trustees are very supportive and often active in our work, such as helping out with family days. Some of us have personal experience of living with inflammatory bowel disease or being the parent of a child with Crohn's or colitis.



## conditions of employment

|                            |  |
|----------------------------|--|
| <b>job type:</b>           | full time, temporary for one year with possibility of becoming permanent, subject to funding   |
| <b>hours</b>               | 35 hours per week, usually Mon to Fri office hours but with some evenings and weekends, and flexibility to adapt to the needs of families and their commitments, such as work and school hours.  |
| <b>salary</b>              | £32,000 per annum  |
| <b>pension</b>             | 3% contributory NEST pension   |
| <b>holidays</b>            | 25 days' holiday per annum, in addition to public holidays. We also close for three days between Christmas and New Year, and you don't need to book this using your allowance.   |
| <b>location</b>            | home-based (office equipment will be provided) with UK wide travel including regular visits to the CICRA office in Sutton for team meetings and 1:1s with the CEO and travel to deliver workshops or facilitate sessions at CICRA family days. |
| <b>transport</b>           | car mileage allowance/travel expenses  |
| <b>probationary period</b> | 3 months   |
| <b>accountability</b>      | reports to the CEO   |

Please note: this role will require an enhanced Disclosure and Barring Service (DBS) check.

## equal opportunities

We are committed to equal opportunities. We actively encourage applications from all sectors of the community and any decisions on recruitment and selection are based solely on job-related criteria and the needs of the organisation.

## appendix one: job description

|                   |   |
|-------------------|---|
| <b>job title:</b> | <b>Family Support Worker</b>  |
| <b>purpose:</b>   | to provide emotional and practical support for children with crohns and colitis, and their families |
| <b>job type:</b>  | full time, temporary for one year with possibility of becoming permanent, subject to funding        |
| <b>hours:</b>     | 35 hours per week, usually Mon to Fri office hours but with some evenings and weekends              |
| <b>location:</b>  | flexible: home based with UK-wide travel inc CICRA office   |
| <b>salary:</b>    | £32,000 p.a. + pension  |

CICRA is the charity for children with crohns and colitis. Our vision is childhood unlimited by inflammatory bowel disease. Our mission is to lead research into better treatments, to support children and families with relevant information and advice, to work with health professionals to improve care and to give children a voice to increase public understanding.

This post is an important new role at the heart of our work to increase emotional and practical support for children living with these serious, debilitating diseases. The role holder will initially deliver a Global's Make Some Noise funded project to develop our support services by helping young people and their families.

### the post

This role will have a dual focus of providing direct one to one support to children and families and helping to develop our wider support programme to support the needs of children and families. In particular, this role will:

- provide direct support to children, parents and siblings
- facilitate sessions at our family information days
- increase support available through our website and telephone helpline
- develop and increase our information on emotional and practical issues
- support the development of our network of support groups

You will help parents and children with a range of issues:

- meeting the emotional, physical and developmental needs of children and young people
- promoting positive experiences and progress for children and young people with IBD
- protecting the welfare of children, young people and their families
- enabling the children, young people and families to build resilience to cope with IBD

### **about you**

You will have experience of working with children and families, in health, education or community settings.

You will be able to organise your own workload and demonstrate initiative

You will be able to deal tactfully with potential conflict.

You will be capable of accurate reporting and the communication of sometimes complex information to a variety of audiences.

You will be passionate about maximising a child's life chances.

You will care.

### **principal responsibilities**

1. To offer practical and emotional support, enabling families to help themselves, and supporting parents or carers
2. To lead on our support for families in the following areas:
  - a. Direct, face to face or telephone/videolink support for children and families
  - b. Facilitate sessions at our family information days
  - c. Facilitate digital sessions to provide support remotely to groups or individuals
  - d. Help with the development of our network of support groups to give children and families a local, peer network for mutual support
  - e. Advise and train CICRA staff and volunteers to enhance support across the charity
3. To work supportively with families, including the extended family, to ensure children's needs for care and security are met by developing agreed action plans with them.
4. Help plan creative and innovative responses of families' and individual's needs, keep high quality records and assist with the preparation of reports.
5. Take the lead in running and developing group work to meet the identified needs of family members.
6. Ensure that work is carried out in a manner which is consistent with CICRA policies and procedures.
7. To attend regularly and participate actively in team meetings and other meetings that might be arranged.
8. To ensure you have a good understanding of, and comply with, CICRA's procedures for promoting and safeguarding the welfare of children and vulnerable adults.

## appendix two: person specification

This outlines the main attributes needed to adequately perform the role specified. In drawing together the specification, a critical examination of the job description has been undertaken to pinpoint those elements of the post deemed as essential. It will be used as part of the recruitment process in identifying and shortlisting candidates.

Those marked 'E' for essential must be demonstrable in the supporting statement or at the point of interview, those marked 'D' are desirable.

|  |   |   |
|--|---|---|
| <b>qualifications</b>  |   |   |
| Qualification in work linked with children and young people  |   | D |
| Degree in childhood studies, child healthcare, education, psychology, social work OR equivalent experience   | E |   |
| <b>experience</b>  |   |   |
| Extensive experience of supporting children and families in an educational, health, social work or charitable setting  | E |   |
| Project development and management in a child or family-focussed role  | E |   |
| A good understanding of issues linked to confidentiality   | E |   |
| A good understanding of safeguarding policy and practice   | E |   |
| Knowledge and understanding of peer support models and group work.   | E |   |
| Knowledge of the emotional, behavioural and mental health difficulties children and young people can face, the impact these can have, and the different kinds of help available.             | E |   |
| The ability to make information accessible and engaging for different audiences  | E |   |
| The ability to develop and deliver effective training sessions.  | E |   |
| A good understanding of the psychological impact of chronic, long term health conditions on family life  | E |   |
| <b>skills/ability</b>  |   |   |
| Excellent communication, and interpersonal skills, and be able to deal confidently with children and adults at all levels, parent carers, professionals and other voluntary sector partners. | E |   |
| Excellent written, IT and presentation skills.   | E |   |
| Ability to analyse data and research trends and patterns   |   | D |
| An understanding of working as part of a team, including with external agencies and parents  | E |   |
| Willingness to take responsibility for continued professional development  | E |   |
| Full driving licence and access to a vehicle   |   | D |

## appendix three: recruitment timetable and process

### how to apply

Please submit a copy of your CV with a two page supporting statement outlining why you are interested in the opportunity and how you meet the person specification, **by 25<sup>th</sup> February 2019**, to [recruitment@cicra.org](mailto:recruitment@cicra.org)

Please also provide the names, positions, organisations and telephone contact numbers of two referees, relevant to this role. References will only be taken once your express permission has been granted.

We would also be grateful if you could let us know if you will require any special provision as a result of any disability should you be called for interview.

Please ensure that you have included a contact telephone number, as well as any dates when you will not be available or might have difficulty with the indicative timetable.

Deadline for applications: **Monday 25<sup>th</sup> February 2019, 12 noon**

First round interviews: **week commencing 11<sup>th</sup> March**

Second round interviews: **week commencing 18<sup>th</sup> March**

**Please be aware, only candidates shortlisted for interview will be notified.**

Interview dates may be subject to change and candidates will be advised in advance should this happen.

If you have any questions on any aspect of the appointment process, need additional information or wish to have an informal discussion, please email Nick Posford, CEO, [nickposford@cicra.org](mailto:nickposford@cicra.org) to arrange a time.

*(no agencies please)*

## appendix four: home working

This role was developed to be home-based because some aspects (such as support group development, workshops and family days) will take place around the country. There is therefore no requirement for the successful candidate to be based in the CICRA office in Sutton, though regular travel for team meetings at the office and 1:1s with the CEO will be required.

We will provide all necessary equipment such as a phone line, computer, broadband, desk and chair if required, and cover all work-related travel expenses in line with our expenses policy.

With a generally agreed pattern of work with your line manager, if you're home-based your working day starts either at the point you start working in your office (i.e. logging on to your computer and telephone) or when you leave your home to attend a meeting, visit a client, etc. We would expect these to usually fall within office hours such as 9-5 with an hour for lunch but as this role requires some evening and weekend working, there will be a degree of flexibility in your start and finish times, subject to line manager approval.

Positive reasons for working from home:

- **work-life balance** Your work is on your doorstep. At either end of your day you can arrive at work and be home in minutes!
- **cost** You can save time travelling and you'll have no commuting costs.
- **flexibility** You will have a degree of flexibility, subject to line manager approval, in planning your working week (apart from cases where your attendance may be required, for example at team meetings, family day meetings etc) within the boundaries of your weekly contracted 35 hours and standard working hours agreed with your line manager.

We're aware that there can also be some disadvantages to working from home:

- you may potentially feel remote from your colleagues, your line manager or the organisation generally

- some people find working from home isolating
- you may feel that practical problems, for example not enough space or not enough quiet/private time, make it difficult to work or concentrate at home.

### practicalities of working from home

If appointed, we would advise you to contact your home insurers to notify them that you are going to be working from home.

Our salaries are as advertised for the role and there are no additional payments. You will not have to pay more tax and in fact, you may be entitled to a small tax allowance for working from home. You'll need to contact the Inland Revenue directly once you are in post with us, and notify them of your circumstances.

We'll provide you with all of the necessary equipment to work at home, but it's your responsibility to make sure that you have the space and the quiet time to carry out the role.

We do not offer a lease car or a cash equivalent but if you use your own car for work purposes you will be able to claim for your business mileage at HMRC rates.

If you have your own desk and chair which you would prefer to use, then you may be able to do so. However, we do have an obligation to ensure as part of our health and safety procedures that they meet appropriate legislation and policy requirements.

**If you require any further information or would like an informal chat about the role, our organisation or our future plans, please email our CEO to arrange a time.**

**Nick Posford**  
**E: [nickposford@cicra.org](mailto:nickposford@cicra.org)**



**cicra** 

better lives for children with crohns and colitis

CICRA is the operating name of  
Crohns in Childhood Research Association,  
a registered charity in England and Wales  
(number 278212) and Scotland (SC040700)