

Understanding
chromosome
disorders

Unique



Adopting a Unique child



rarechromo.org

Adopting a 'Unique' child

Introduction

This guide is designed to provide information for adoptive families and those who are considering adopting a child who is 'Unique' through a chromosome or genome disorder. You may be considering a link with a child, have a child in placement, or have previously adopted a child. In this guide you will find information on support available and links to useful sites that may be of interest.

Please note: This guide is based on adoption in England and can vary greatly in other countries. In Scotland and Wales the exact process and names of forms are all slightly different, but this guide may be helpful. It is recommended that you contact your local Social Services Department for fostering and adoption if you reside outside the UK.

“.....all children, including those with impairments, have a right to be seen as unique individuals. They also have a right to a family - and to make that more likely, potential families must be shown through every means possible, that each child is more than a label or diagnosis..... ”

(Cousins, 2009).

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Considering a Unique child

Many prospective parents are looking for a child or children that fit their family group and the ideals they hold of what life will be like loving and raising one or more children through adoption. A family wishing to provide a home for a child with additional needs will often have experience with other children of varying abilities and needs. It is very important to remember that children who are released for adoption by the court system have already experienced trauma by leaving their birth family and the life that they have known. Even a new-born baby has experienced the profound loss of its mother if separated at birth. For a child that has a chromosome or genome disorder this can be evident in the way they have been cared for or the way they are able to understand, communicate and express themselves.

As chromosome and genome disorders are so unique in the way they affect each individual emotionally, psychologically and physically their needs can be vary varied. Some children require little or no intervention. Others require a plethora of medical equipment and specialists and a lifetime of hospital appointments and surgeries. It is very difficult to predict the future of a child with a chromosome or genome disorder and serious consideration should be made as to whether you are willing to care for a child long past the point where most children leave home and branch out on their own.

There is a point at which you will have been asked by, or have worked with your social worker, to narrow down and rule out what you can and cannot accommodate when bringing one or more children into your forever family. A social worker should discuss with you the needs of the children that you are willing to consider, including their medical conditions, disorders, experiences and childhood traumas.

There are a lot of things that you should consider very carefully before progressing with a link towards matching panel. Included in this guide are questions that are advisable to ask yourself and to ask the professionals when you meet with the medical advisors and carers of the child/ren you have been linked with.

If you are reading this guide because you have already adopted or have a child in placement, you may wish to skip ahead to the relevant sections, or browse through the other information guides that **UNIQUE** has compiled, you may well find one that is similar to the chromosome or gene disorder of the child you are adopting, or considering adopting.

If you would like to be put in touch with Unique registered parents who have adopted a Unique child, please contact Marion Mitchell, Unique Family Support Officer, email: marion@rarechromo.org

For a family that have a birth child with a chromosome or genome disorder they have a choice to parent the child or allow someone else to parent the child. Sometimes a parent or birth family isn't able to meet their child's needs, especially if those needs are complex. This may occur for any number of reasons, including that they may not have the necessary network of support and the ability to do so.

“ There are wonderful things that a Unique child has to teach us. I have learned that each moment, each breath is a gift. To treasure each and every moment from a simple smile which I can remember when I figured out that she was crying because she need her bottle at 15 months old and couldn't communicate, to now hearing “Mom, I want to talk to you about some songs,” and spending time with her as she shares with me some of her current favourite songs and artists on YouTube. These children teach us the gift of the moment, the gift of life's simple pleasures, and that every day is a celebration not just the graduations, marriages, and “firsts.” Simply waking up and having your child smile at you is one of the greatest lessons.”

Questions to ask yourself.....

- ◆ **How would I feel if I couldn't work because my child needed me at home?**
- ◆ **Am I ready to be a full time stay at home parent carer?**

It is easy to say that you would happily stay at home to care for your child. Think seriously about the reality of giving up a well-paid job or a job that you love. It is normal for any stay at home parent to wish they were back at work when the days get hard, even more so for a parent of a child who is Unique, which combined with the guilt of these feelings can be a heady combination. You may not have the choice of returning to work after your adoption leave ends if there aren't any suitable childcare facilities in your area.

- ◆ **What will be the financial impact if you have to give up work?**

“ Financially we are okay with me not being at work, as my child was awarded DLA and because of that award I was able to claim carer's allowance, but there are days when I resent that he gets to go to work and leave all this behind. There are days I miss my old job and wish that life was different. It doesn't make me a bad mum. It means I'm human. I've learnt to forgive myself and I can live with that. ”

◆ **What kind of support network do I have?**

Who will be around to support you and your child/children? There's an old saying, "it takes a village to raise a child" which in this case can be very true. Think about the needs of the child/children you are looking to adopt. If you are considering a sibling group, think about who will care for your other children during medical appointments and reviews.



◆ **Who will look after your child when you are ill?**

If you are a single adopter most agencies will look carefully at your support network and at how you will be supported in all areas of your life. Think about your needs as an individual and how you will make time for yourself. If you are a couple, think about how you will make time for each other. Many people will be willing to help look after your child, but not everyone will understand their need for additional support. You need to feel comfortable with them being able to look after your child with their complex needs which may include both medical needs as well as communication difficulties.

◆ **Who will take care of your child if a regular babysitter isn't suitable or if your child has complex needs?**

◆ **Is there respite included as part of the support package?**

◆ **What is the psychological impact?**

Caring for a child with a chromosome or gene disorder can be difficult, yes, but also incredibly rewarding. They often have a great sense of humour and are very caring. There is a darker side to adopting a child who is Unique. Consider that the child might not be able to communicate their needs and feelings. They might not be able to show emotions or affection in the usual way. They might also reject you showing them affection. Think about how you will talk to people about your child, how you will answer their questions or deal with their sometimes very insensitive comments towards your child/children.

◆ **How will you feel in 5, 10, 20 years' time when all your friends and family have children who may be achieving GCSE's, degree's, new jobs, learning to drive, marriage and children of their own?**

“ We are currently coming to terms with the fact that we will always need someone to look after our daughter. She will need a 'babysitter' even as a teenager and an adult, if we want to do something together alone as a couple. ”

◆ **Is my home suitable?**

Think about the physical needs of the child that you are looking to adopt. They may still be in a normal children's pushchair at the moment.

- ◆ What happens when they are too big for one?
- ◆ What if your child never walks?
- ◆ Do you have room for a wheelchair and are you able to carry and lift a heavy child or adolescent?
- ◆ Will you need a hoist or specialist chair?
- ◆ What about a downstairs room or stair lift, adapted vehicle to take them out and about?

There is a wide variety of equipment available to buy or hire and charities that can help with funding towards larger items.

- ◆ Are you okay with the possibility to always having to keep your home child-proofed?

◆ **Can I cope with seizures, tube feeding and adult incontinence?**

It can be easy to think that caring for a small child with a chromosome or gene disorder will continue to be simple, or that they will go on to lead a fairly normal and independent life, which does happen. Think about going out to dinner and how you will feel if your child is tube fed and isn't able to eat the food that is being served.

- ◆ How would you feel about having to take oxygen tanks with you whenever you go out?
- ◆ Where would you change a large child or adolescent that is still using nappies and pads?

Think ahead to puberty and the challenges that will bring. Take time to carefully consider how this will impact you, your relationship and your support network of family and friends.

Think about having to plan family holidays or even simple shopping trips around needing to take specialist medical equipment with you. Think about having to plan around medicine schedules if they need to be taken at certain times. Look into insurance for trips or medical equipment, this can sometimes double the cost of your holiday. If your child has mobility equipment prescribed by the NHS you need to insure it against loss and damage or you would be liable for its replacement and repair, especially if you are abroad.

“ We were invited to meet with the geneticist before we went to matching panel. Unfortunately, she didn't have any more information than what we had already received from Unique. But it was good to have been there, it prepared us for the fact that adopting a child with a rare chromosome disorder it is not straight-forward and the medical professionals won't always have answers. This is something to consider before adopting a Unique child, how you might think you are going to cope with the prospect of the child's future being uncertain. ”

Being linked with a child

When you have been linked with a child and are working through the process to get to matching panel you should eventually have the opportunity to meet with the child's local authority adoption panel medical advisor, foster or relative carer(s) and any other professionals that may be necessary in helping you get an informed picture of the child you are wishing to adopt. It can be helpful to write a list of questions that you might need answering so that you don't forget anything on the day. Remember that there is no such thing as a stupid question and that the more information and understanding you have on the child's needs, the better you are able to make a decision as to whether you are the right parent(s) for the child and they are in turn the right child or children for you.

After Matching panel

After you have been to matching panel and you have been officially Approved, the fun really begins. It's normally only a few days between panel and meeting him/her/them for the very first time. Take the time to write down any things you feel you may need to ask the carer about the child's routine and be prepared to jump in with both feet. The most important thing during the matching process is to speak up if something doesn't feel right. It could be as simple as needing to put external support in place, or having services transferred to help the child with continuity. It could also be that the child is more complex and requires a lot more intervention and support than you realised. It's very hard to know before you meet a child what you are really facing. Believing that you can do something you read on paper is very different to having to do it 24 hours a day - 7 days a week, 365 days a year.

It might be that you just don't click. Feeling something is missing. Don't keep quiet. Talk to your social worker about it. It is far more damaging for both you and the child if the placement breaks down at a later date. You will have a meeting after matching panel to plan introductions. Think ahead to what you will do for the first few days when you are only with them for a short period of time. It's good to spend that time relaxing and recharging, introductions can be a very emotionally exhausting time. At the end of each visit write down any questions you might have. Ask the carers to write down the child's routines, like meal and sleep times and medical requirements, including when and how much, if any medication is needed. During introductions offer to help out as much as possible (and as much as the child is willing) with the practical care of the child, so that the child becomes accustomed to the way you do things. Take time to find out their likes and dislikes as age appropriate; such as movies, tv shows, music and hobbies.

The child will be out of their comfort zone. It will be good for both of you if you can get them to feel as comfortable as possible with their basic care.

If you are adopting more than one child, ask to have time individually with each child to get to know them; as well as the sibling group together.

“ We had a potential match with a beautiful little boy. We knew he had an anomaly on chromosome 16 and we’d done a bit of research. We got quite far into the process and then it turned out that there was a medical need we were simply unable to meet. Whilst it was devastating, asking the right questions before we got too invested saved a lot of heartache for everyone. ”



“ We were really lucky that our adoptive daughter had a really good, proactive social worker. She arranged for us to visit her nursery to meet staff and observe (but not interact with) her in the setting. At the same time, we met with Local Authority SEN advisors and the foster carer. This gave us a good picture of where she was at developmentally and what her educational needs were at the time, but they couldn’t tell us much of the prospects for her future. Most importantly it gave us the chance to see her interact with the adults that cared for her, especially the foster carer. It showed that she had made a good attachment to her carer and that she would most likely be able to make attachments to us too. ”

BRINGING YOUR UNIQUE CHILD HOME

You're finally home with your child/children. It is normal for them to regress considerably as they come to terms with their new environment and being around you. Keep at the front of your mind that although you have known about this child for some time and that you have looked into every aspect of their life, you are still a stranger to them. They have only known you for a short while and this is very daunting for them. Add into the fact they may have additional or complex care needs and it can be a very emotional and trying time for everyone. You will have visits from both the Local Authority and your Social worker during the first week and weekly visits for the first few months. Those visits will then drop to monthly and things will seem a little more settled. It is normal in those first few weeks to feel like you are under a microscope. It is the perfect time to be asking questions and getting services transferred. Some people find it useful to keep a diary, others talk to family and friends about how they are feeling. It can be overwhelming for people who haven't had children around them before. Going from a quiet house with time to yourself to suddenly having a little person needing you all the time can be quite an adjustment.

“ I had post-adoption depression a few months into our placement. I didn't realise it at the time. I was physically, mentally and emotionally exhausted. It took a little while for me to come to terms with the difference between what I thought our family would be and how we actually are. I love my girls so much and I wouldn't change my life for anything, but it was hard. The first few months were a whirlwind. What seemed at the time to last forever, now feels like it went by in the blink of an eye! ”

Try and get a support network in place for when you come home. Get family and friends to understand that you won't be as available whilst you all start to bond and settle into your new family life. If you have other children, make sure they have a support network of their own. Plan for them to have a bit of respite whilst you all settle in and get to grips with your new home life. Maybe they can go to a friend's house for tea or have a sleepover at a grandparent's house? Make up dinners and lunches and freeze them in advance so that you can heat them up in an oven or microwave. This will give you time to spend as a new family getting to grips with and adjusting to your new routines. Try to prepare in advance as much as you can for bringing your child/children home. Not only will it help in the long run, but it also provides a good distraction for you whilst you wait with excitement and anticipation at bringing your little one home. When your child's adoption is completed, they will change NHS

number. Due to many UNIQUE children having multiple medical appointments and interventions, it is really important to follow up that all services are transferring all old notes over to their new journal. Some departments are really efficient and others are not. You don't want to miss out on any appointments due to this, or having to wait to be re-referred, as medical interventions might be vital to your child's wellbeing.

“ Whilst she was in care she would not let anyone besides the female foster carer feed her. The first time I tried to feed her she refused, and I was devastated, thinking I would not be allowed to bring her home if she wouldn't let me feed her. That evening she cried until she vomited all over me. Two days later she let me feed her yoghurt. And with a lot of tenacity from my side and ketchup, I managed to feed her a couple of spoonfuls.”



“ I felt so guilty to start with. I felt like I couldn't tell people how hard it was trying to parent a disabled child. She'd come to live with us at the age of 3 and had experienced trauma and neglect. At the time, I felt like I didn't have the right to complain how hard it was. I felt like a failure and a fraud. It was awful. Even though we knew she had a chromosome deletion, we had no idea how rare it was and what the impact of the adoption would be on her, on us and on her sibling. We are very fortunate that she is thriving and that we have a great support network around us.”

ACCESSING SUPPORT

It is advisable to access any support that you can. Raising a child with a chromosome or genome disorder is not easy. It is incredibly rewarding, challenging and sometimes frustrating. You are likely to become excellent at dealing with all the red tape, a pro at fighting to access services, therapies and support for your child. Being able to access any support will help to make your life easier and more enjoyable.

During your meetings with your social worker they will have discussed with you about the support that will be offered. This should be done before introductions though you can amend it after placement if you feel that it needs it. You have to wait a minimum of 10 weeks before you can put in the application to legally adopt a child in most areas of the UK. It is normal for people to wait longer. It is a great time to look at the support that the Local Authority are offering your child/children and tailor it to meet their needs as they grow, not just immediately but ongoing into adulthood. They have a legal responsibility to each child for 3 years post adoption. That's 3 years from the date the adoption order is granted, not the point at which they are placed with you. Some Local authorities may offer longer as part of the support package. Some local authorities will offer financial support or provide specific services for a period of time.

Once your child is home with you, if you feel more support would be needed, or the support that has been offered needs to be extended, do not be afraid to ask. After all if you don't ask you don't get. The worst they can say is no.

“ I called the GP to make an appointment for my daughter, only to be told that she was no longer registered with them due to the change of NHS number. So I had to re-register one of my children, but not the other one. My daughter's paediatrician told me that in the 20 years she has worked with families with looked after and adopted children, the transfer of information between NHS numbers has always been a problem.”

FRIENDS AND FAMILY

Your support network of friends and family might not have experience of children with special and additional needs. And however willing they are to support you, there are some things that you would be best supported with through expert services or by families experienced with additional needs. It might be useful to get in touch with local SEN support groups before your adoptive child (ren) are placed with you, so you know where to turn for more specific support when you need it. A local special needs school might have a group you can attend or they may be able to point you in the right direction.



to ask the Professionals.....

- ◇ What specialists, consultants and doctors do they see?
- ◇ How often do they have these appointments?
- ◇ Who will ensure that the medical aspects are transferred to the relevant local services at placement?
- ◇ What support does the child currently access and will it be transferred? (Younger children often access Portage before nursery).
- ◇ Do they attend a nursery, if so, is it special needs or mainstream?
- ◇ Do they attend a mainstream school, and is it a specialist unit within the school or, do they attend a special needs school?
- ◇ How will they support the child's transition into a new school or nursery environment?
- ◇ What is their routine like?
- ◇ How do they sleep and how much support do they need during the night?
- ◇ What food can they eat?
- ◇ If they can't eat are they fed using a gastro tube (into the stomach or nasogastric tube (into the nose)?
- ◇ What brand of formula do they use?
- ◇ Are they still in nappies? And if so are they in receipt of an NHS supply? This varies between Local Authorities. Some start at age 3. Other places you have to wait until the child is 4 or 5 years old. The incontinence team or child's health visitor can help you get an assessment and free nappies delivered to your home.
- ◇ What ongoing support will the local authority offer you? Both during placement and after adoption?
- ◇ Will there be a grant for any equipment that may be needed?
- ◇ Is the child in receipt of DLA for Children (Disability Living Allowance)?
- ◇ How do they travel?
- ◇ Do they have to have a special seat or restraint?
- ◇ If they are using a wheelchair, who does the wheelchair belong to? Was it purchased or issued on loan?
- ◇ Will there be help with an adapted vehicle if necessary?
- ◇ Do they have a Motability car (achieved through the child's DLA mobility component) and how would that transfer?

More Unique parent quotes.....

“ Adopting a child is full of so many unknowns. Lack of information about their history, lack of predictability about their future needs, to then throw genetics in the mix seems like an impossible task. My daughter was placed with me at a year old with some development delays and an expected diagnosis of foetal alcohol syndrome. Within weeks of placement that was all still true but I was additionally thrown into the world of chromosome disorders.”

“ Her condition isn't life limiting but will have a long-term impact on her physically. It's nowhere near as scary as it looks on paper. It's too soon to know how severely she is affected, so sometimes I find it hard to get my head around it and panic about the future. But for now she is doing great. A little behind her peers but determined to catch up.”

“ To be honest, I wouldn't have adopted her if I had read about it on paper. But in reality I am more than capable, willing and happy to take everything on we have now and enjoy her for the beautiful, funny, strong willed girl she is.”

“ Science is not my strong point and I knew nothing about genetics. So to be told that she had a chromosomal deletion was a complete surprise and very overwhelming. Because it was rare, her paediatrician could only give me limited information and Google was even more complicated than that. I knew nothing, even with a diagnosis.”

“ I linked up with Unique and learnt a bit about genetics, connected with other families with different genetic issues and quickly became an expert in her diagnosis.”

“ In many ways it's the simplest of our 'issues' because it's medical and fits neatly into the medical system. We are well supported by health and social care.”

LINKS.....

◆ **Adopting (USA)**

www.adopting.com/

A large US-based internet resource on adoption and adopting.

◆ **Adopting Kids with Medical Needs**

www.facebook.com/groups/992338597563407/

A facebook group for people to discuss concerns, challenges, share helpful tips or get ideas from other parents who have adopted children with medical needs.

◆ **Adoption UK**

www.adoptionuk.org

Facebook: www.facebook.com/AdoptionUK/

⇒ England: 07904 793 974 and 07539 733079

Monday to Thursday 10.00am - 2.30pm and Friday 10.00am - 12.30pm

⇒ Northern Ireland: 028 9077 5211

Monday to Thursday 10.00am - 4.00pm and Friday 10.00am - 2.30pm

⇒ Scotland: 0131 201 2489

Monday - Friday 10.00am - 2.30pm

⇒ Wales: 02920 230319

Monday - Friday 10.00am - 2.30pm

A charity providing support, awareness and understanding for those parenting or supporting children who cannot live with their birth parents.

◆ **Adoption, search, support, England only**

www.facebook.com/groups/adoptionsupportenglandonly/

A group created by parents.

◆ **CORAM BAAF Adoption and Fostering Academy**

<https://corambaaf.org.uk>

020 7520 0300

Providing support and information for both adoption and fostering. They have many resources including information leaflets. They run training and events as well. They also have several books available to purchase on Adoption, including:

◆ **Adopting a child by Jenifer Lord**

This beginner's guide is the book for anyone considering adopting in England, Northern Ireland and Wales. This book will guide you through the adoption process, reflecting current legislation and guidance, with real life adoption stories.

◆ **Our adoption journey by Jayne Lilley**

Published as part of the Our Story series, this is the true story of Jayne, Dan, their son Charlie, and their adoption of Jessie, a baby girl. Told by

Jayne, this memoir follows the joyful highs and heart-breaking lows of the journey that led them to their new adopted daughter.

◇ **Talking about adoption to your adopted child by Marjorie Morrison**

How can I start talking to my adopted child about their past? What information do children need at different ages? What if my child has difficult or painful experience in their past? Talking about adoption will help you find answers to these tricky questions.

◇ **Related by adoption by Hedi Argent**

This useful handbook introduces grandparents-to-be and other relatives to information about adoption today. It offers some facts about the children who need to be adopted and discusses how the wider family can support and be involved in building a family through adoption.

◆ **DLA - Disability Living Allowance for Children**

www.gov.uk/disability-living-allowance-children

A government benefit that provides financial help for children with additional needs. This is awarded based on the needs of a child that are above and beyond the needs of an average child of the same age. It can be applied for by a carer or appointed person of the child and can be transferred over when the child is placed with you.

◆ **Education Support for Adopted & LAC (UK only)**

www.facebook.com/groups/246794772470125/

This group aims to share educational knowledge, school issues, mental health support and fight for services to recognise our children. You must be an adopter/foster carer with kids in placement or just about to be placed parents/carers only please. No professionals.

◆ **Fertility friends**

www.fertilityfriends.co.uk/

A UK based website for people concerned with Infertility, Adoption, parenting after infertility and moving on.

◆ **First4adoption**

www.first4adoption.org.uk

0300 222 0022 Monday to Friday 10am to 6pm

Email: helpdesk@first4adoption.org.uk

A dedicated information service for people interested in adopting a child in England. If you have a question about your suitability to apply to be an adoptive parent, or if you want to know where to begin the adoption process, call their trained advisers who will be able to give you the information that you need. They can also put you in touch with adoption agencies in your area. First4Adoption is run by the charities Coram,

Coram Children's Legal Centre and Adoption UK. It is funded and supported by the Department for Education. All calls to this service are confidential. This service is provided in England only.

◆ **Fostering Network**

www.thefosteringnetwork.org.uk/

For information or advice on fostering, please get in touch.

- ⇒ England (members of The Fostering Network only) 020 7401 9582
- ⇒ Northern Ireland 028 9070 5056
- ⇒ Fosterline Scotland 0141 204 1400
- ⇒ Fosterline Wales 0800 316 7664
- ⇒ 24-hour legal helpline 0345 013 5004
- ⇒ Stress counselling helpline 0345 074 2799

Membership charity that provides information and resources, impartial advice, training and conference events for foster carers and fostering services across the UK. Also campaigns about issues related to fostering.

◆ **Hadley Centre for Adoption & Foster Care Studies**

www.bristol.ac.uk/sps/research/centres/hadley/

Aims to promote best practice by linking research, practice and training in order to provide children whose own parents are not able to care for them consistently or predictably with stability and permanence.

◆ **Motability**

www.motability.co.uk

A car and scooter scheme for people who receive the higher rate component of DLA. As a parent of a child on higher rate mobility, you can exchange your benefit for a vehicle under a hire agreement for 3-5 years.

◆ **NHS Choices**

<https://bit.ly/2O38DrS>

The NHS guide to the health, well-being and support available to adoptive families. During the adoption process, it is important to find out what support package will come with your child to help with any special or additional needs they may have. Some needs may not become apparent until later, perhaps during adolescence, so it's important that you know where to go should you need support at any time. Adoptive families have a legal right, as and when they request it, to a Statutory Assessment of Support Needs from the local authority responsible for their post-adoption support. The assessment covers a range of needs, from mental health and the need for therapeutic services to additional support during a child's education. This is in addition to the financial benefits and allowances that all families, depending on their circumstances, are entitled to.

◆ **PAC-UK**

www.pac-uk.org/

⇒ **London office Advice Line:** 020 7284 5879

Monday, Tuesday & Friday 10.00am-4.00pm

Wednesday & Thursday 2.00pm-7.30pm

⇒ **Leeds office Advice Line:** 0113 230 2100

Monday, Tuesday, Thursday & Friday 10.00am-1.00pm

Wednesday 4.00pm-7.00pm

⇒ **Education Advice Line:** 020 7284 5879

Wednesday & Thursday 10.00am-12.00pm

Their purpose is to provide anyone who has been affected by adoption or other forms of permanent care, as well as the professionals who support them, with expert, independent advice and counselling.

◆ **PAFCA** (Parenting Advice for Foster Carers & Adopters)

www.pafca.co.uk/

Email: contactus@pafca.co.uk

Parenting Advice for Foster Carers and Adopters (PAFCA) joins together the expertise of foster carers and adopters with that of professionals to improve the emotional well-being, behaviour and mental health of adopted and fostered children.

◆ **UK government information**

www.gov.uk/child-adoption

UK Government guide to adoption, including links to other relevant Government resources and services.





NOTES

You might find it helpful in your journey to write down any notes or other questions you wish to ask.....

ANSWERS TO MY QUESTIONS

You might find it helpful to write down answers you receive to the questions you ask.....

Inform Network Support



Rare Chromosome Disorder Support Group
The Stables, Station Road West, Oxted, Surrey RH8 9EE,
United Kingdom
Tel: +44(0)1883 723356
info@rarechromo.org | www.rarechromo.org

Join Unique for family links, information and support.

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at www.rarechromo.org
Please help us to help you!

Our thanks to all of the parents that contributed towards this guide.

Version 1 (EY; MM)

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