Progressive Familial Intrahepatic Cholestasis (PFIC) 
a guide
Welcome

This leaflet has been written for:

- Parents/carers of a child with PFIC
- Young people with PFIC

Others who may find this leaflet helpful are:

- Relatives and friends
- Healthcare and allied professionals, school, college, university and nursery teams

This leaflet aims to:

- Explain more about PFIC
- Explain treatments

PFIC is a group of conditions therefore not all the information in this leaflet may be relevant for your child/you. The specialist and the team will guide you on this.

You may find it helpful to read the following CLDF leaflets:

- Guide to the liver
- Glossary of terms
- Routine investigations for liver disease

Children’s Liver Disease Foundation (CLDF) also has leaflets in its support series which are available to download from our website – childliverdisease.org. Leaflets can be mailed to UK patients free of charge, our contact details are on this leaflet. You may find it helpful to have a copy of CLDF’s making the most of an appointment leaflet which will help you prepare for appointments and meetings following discharge.

We also have the following information packs available, free of charge:

- Essential 5 – CLDF’s starter kit of vital information
- Education – a pack supporting children and young people under 18 in an educational setting
- GP Practice – a pack for families to give to their GP providing a range of information on childhood liver disease
- Friends and Relatives
- Yellow Alert – a pack to support CLDF’s Yellow Alert Campaign for early diagnosis of liver disease in newborn babies

All are available on request to UK families and young adults.

Overseas families should contact CLDF to discuss their literature needs.
What is PFIC?

PFIC or Progressive Familial Intrahepatic Cholestasis is the name which has been given to a group of inherited conditions causing cholestasis (reduced bile flow) in children/young people. The bile flow is reduced either because the liver cannot make bile properly or because it cannot get it out of the liver cells into the bile ducts, or both. The bile ducts themselves may also be abnormal reducing the flow of bile through them. Recent research has led to a better understanding of these conditions but the research is still continuing.

What is bile and why is it important?

Bile is a yellow/green liquid which is made in the liver. It contains:

- Bile acids which act like detergents to break down the fat in the diet
- Conjugated bilirubin, a waste product produced during the normal breakdown of red blood cells. This gives bile its colour.
- Cholesterol
- Other lipids (fats)
- Water
- Other waste products

And small amounts of other substances.

Bile flows out of the liver through the large bile ducts and is stored in the gall bladder where some of the water content is reabsorbed. When we eat, the gall bladder contracts pushing bile back into the large bile ducts and down into the duodenum — the first part of the intestine (bowel). See diagram 1.

Bile acts like the detergent in a washing up bowl. Bile plays an important part in breaking down the fat in the food we eat into very small particles, so that we can digest it, use the energy in it and absorb the fat-soluble vitamins it contains.

Further down the intestine, in the section known as the terminal ileum, most of the bile acids are reabsorbed through the bowel wall into the blood stream and return to the liver to be reused. Bile is also responsible for colouring the stool and making it less smelly.

How is bile made?

In the liver each of the billions of cells is in close contact with tiny blood vessels, called capillaries, which carry a mixture of the blood coming from both:

- branches of the hepatic artery bringing blood carrying oxygen which is important to keep the cells healthy and able to function
- branches of the portal vein, bringing blood containing substances digested from our food and drink in the intestines.

Many complex processes take place in every liver cell.

The waste products from each cell are taken away by:

- the tiny blood vessels (capillaries) which each drain into a branch of the hepatic vein and these return blood to the heart
branches of the bile duct system which remove water, conjugated bilirubin, bile acids, cholesterol and other substances which together make up the bile. See diagram 2 above.

The liver cell requires a large number of special ‘pumps’ to move substances in and out of the blood and into the bile.

What are the possible effects of PFIC?

The type and severity of effects vary greatly from one child to another. Effects may include:

- Jaundice
  Some of the conjugated bilirubin trapped in the liver passes back into the bloodstream. It is carried around the body and is responsible for the yellow colouring of the whites of the eyes and the skin, known as jaundice.

- Discolouration of teeth
  Due to jaundice being present while the teeth are forming/growing. The higher calorie diet and/or medicines needed may also contribute to this.

- Darker urine
  Conjugated bilirubin is passed out in the urine making it more coloured than normal.

- Pale, smelly, greasy stools, frequently loose (diarrhoea)
  These may be more difficult to flush away, due to the reduced amount of bile available to colour and deodorise the stools and because the unabsorbed fats are passed out in the stool.

- Failure to thrive
  Poor weight gain and possibly slower growth due to reduced absorption of fats, which usually provide a significant amount of the energy (calories) in a child’s diet.

- Vitamin Deficiencies (especially the fat soluble vitamins A, D, E and K) — due to reduced absorption of:
  - Vitamin K — this is needed to make clotting factors that control bleeding, a deficiency may result in nose bleeds and bleeding from the gums.
  - Vitamin D — this is needed for strong healthy bones and teeth, a deficiency may result in weaker bones and/or rickets.
  - Vitamin E — this is needed for a healthy nervous system and the development of co-ordination.
  - Vitamin A — this is needed for good eyesight, particularly to see in the dark and for the eyes to adapt to changing light conditions.

- Enlarged liver
  Due to inflammation and swelling.

- Itching (Pruritus)
  This is not completely understood but is thought to be due to the increased level of bile acids/salts in the blood caused by the bile not being made and excreted in the normal way. There is a CLDF leaflet on itching. Itching may disturb sleep and contribute to:
  - Fatigue, tiredness, irritability
  - Reduced appetite, nausea, vomiting.

Diagram 2: Diagrammatic representation of liver cells

<table>
<thead>
<tr>
<th>To bile ducts</th>
<th>bile drainage away from liver cells</th>
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<tbody>
<tr>
<td>Liver Cell</td>
<td>Liver Cell</td>
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<tr>
<td>Portal vein</td>
<td>Sinusoid</td>
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<tr>
<td>Blood drains into hepatic veins</td>
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Gall stones
This is the name given to the formation of solid particles within the gall bladder or bile duct system. If a stone blocks (obstructs) a bile duct this can cause severe pain and/or increased jaundice. In most cases gall stones are present but cause no problems. Gall stones increase the risk of cholangitis. This is an infection in the bile ducts which causes fever, general malaise/tiredness and can also cause discomfort/pain and increased jaundice.

What are the possible complications of PFIC?
The bile trapped in the liver may cause progressive damage to the liver. This can cause it to become scarred (fibrosed) and hardened which eventually affects its ability to work properly. This is called cirrhosis. The effects of cirrhosis can include:

- Portal Hypertension, enlarged spleen and internal bleeding
  Due to the hardening of the liver there is increased resistance to the flow of blood from the intestines into the liver through the portal vein. This increased pressure can cause enlargement of the spleen and the development of oesophageal varices — swollen blood vessels in the lining of the oesophagus (foodpipe) — which may result in internal bleeding.

- Ascites (fluid retention in the abdomen)
  Due to increased pressure in some of the blood vessels, and the reduced ability of the liver to make an important protein called albumin, excess fluid can collect in the abdomen.

Further CLDF leaflets are available on portal hypertension and ascites.

Increased risk of liver cancer
All forms of liver disease increase the risk of liver cancer. Some forms of PFIC have a significantly increased risk.

What tests may be done?
CLDF has a leaflet on routine investigations.

Liver Function Tests
These are blood tests which may help to make the diagnosis. They can also be repeated at intervals to monitor the severity and progression of the disease. They include:

- BILIRUBIN — a measure of the jaundice level.
- ALP (alkaline phosphatase) — may be used to indicate biliary tract inflammation, damage or obstruction. This test is not liver specific and can indicate changes elsewhere in the body.
- AST (aspartate aminotransferase) — liver enzyme which measures the amount of inflammation in the liver cells.
- ALT (alanine aminotransferase) — liver enzyme which measures the amount of inflammation of the liver cells.
- GGT (gamma-glutamyl transferase) — a bile duct enzyme which helps to distinguish between different types of PFIC.
- ALBUMIN — a protein produced only by the liver. A low level can be a sign that the liver has been damaged.
- INR (International normalised ratio) — a measure of the blood clotting, which is controlled by the liver. A raised level which is not corrected by Vitamin K is a sign that the liver has been damaged.

Bile Acid Tests
These are more specialised blood and urine tests which can help to determine the type of PFIC disease. The results take much longer than the more common tests (above) to come through.
Genetic Tests
These are highly specialised blood tests which are still being developed. To carry out genetic testing blood needs to be taken for testing from the child and both parents, if possible. It may be many months before the results are available. In many cases antenatal diagnosis (diagnosis in the womb) can be offered for future pregnancies involving the same parents.

Scans and X-rays
These may be used both at the time of initial investigation/diagnosis and for continued monitoring of the condition and its effects. The following may be included:

- **Ultrasound Scan** to assess and monitor
  - The size and consistency of the liver
  - The spleen size
  - The blood flow into and out of the liver

- **Bone X-rays** — wrist X-rays in particular may be used to look for the early stages of rickets (bone weakness) developing

- **MRI/MRCP** — magnetic resonance imaging/magnetic resonance cholangiopancreatography — this is a form of scanning which uses special magnets to obtain a picture of the internal organs especially the bile ducts

- **Isotope scan** (DISIDA or HIDA scan) to show how well bile is being excreted from the liver.

Liver Biopsy
A small piece of liver tissue is taken out, using a special needle, and then examined under the microscope. An operation is not usually needed. Results from the liver biopsy are used to help make the diagnosis, to assess the severity of the disease and to advise about the future (prognosis). It is not usually necessary to repeat the biopsy.

Dietary treatments in PFIC

Dietary treatments used in children/young people with PFIC will depend on the specific symptoms and characteristics of the individual child.

As explained already, poor bile flow or poor quality bile can result in jaundice and incomplete absorption of normal fats and fat soluble vitamins found in the diet. As fat is a good source of energy, poor absorption of fat may contribute to poor growth and loose stools.

Specific Dietary Treatments:

- **MCT (Medium Chain Triglyceride)**
  MCT fat is absorbed more easily than other fats when bile flow is poor and is a good source of energy. MCT fat is not commonly found in foods but there are specialist milk formulas and supplements, containing MCT, available. Your dietitian can advise you.

- **Fat Soluble Vitamins**
  Fat soluble Vitamins A, D, E, K also need bile for absorption and therefore extra should be given. This is usually given as an oral medicine although an injection may be needed.

- **Nutritional Supplements**
  If your child/the young person is not gaining weight, the dietitian may advise special milkshake drinks which will give additional energy, protein and vitamins.

- **Nasogastric Feeding**
  If your child/the young person is not growing well because of their symptoms then overnight nasogastric feeding may be advised. This would allow additional energy and protein to be given overnight. This involves a very fine, soft tube which is passed up the nostril, down the back of the throat and into the stomach. A specialist formula milk can then be given overnight using a pump. Parents/carers can be taught how to do this at home.
What medicines are used to treat PFIC?

There is no complete cure for PFIC but medicines and/or surgical treatments can reduce the effects and complications of the condition. The treatments to be used will be recommended by the specialist depending on the features and severity of the condition and its effects. Medicines given may include the following.

- **Cholestyramine (Questran®)**
  This helps to improve bile flow thereby removing more bile salts from the body and this may reduce itching, although results vary. Care needs to be taken as it can interfere with vitamin absorption if given together therefore Cholestyramine (Questran®) should be given at different times to any vitamin supplements.

- **Ursodeoxycholic Acid (urso or Ursofalk or destolit®)**
  This may also help to improve bile flow and thus reduce jaundice and/or itching as well as improving liver function. It has been found to be particularly useful in a type of PFIC called MDR3 deficiency (see later).

- **Rifampicin**
  This is a liver stimulant (although it is more commonly used as an antibiotic against tuberculosis). It reduces itching in some patients. Rarely it may cause deterioration of liver function tests; it is therefore used with caution in severe liver disease and liver function tests are monitored to assess its effects. It may also stop attacks in a type of PFIC called BRIC (see later). Of note Rifampicin is strongly red coloured and can cause urine to be pink/red in colour, this is harmless.

- **Vitamin Supplements**
  Especially A, D, E, and K, are usually given by mouth as medicines or tablets but injections are sometimes needed.

- **Phenobarbitone, naltrexone, and ondansetron** are other medicines which have been used with varying degrees of itch reduction in some children.

What else can be done to help reduce itching?

As well as the medicines already mentioned any of the following may be useful and should form part of the overall management.

- Prevent your child/yourselves from overheating, particularly at night — a bath at bedtime may be helpful.
- Keep nails short to reduce skin damage if your child/you scratch.
- Keep skin covered with clothing as much as possible e.g. babygrows for young children — cotton clothes may be best.
- Consider mittens especially at night for younger children (these can be sewn onto the ends of baby-grows to prevent removal by the child).
- Regular use of emollients to keep skin soft helps to reduce skin damage from scratching.
- The use of perfumed bath bubbles/oils or skin lotions may increase itching. Fabric conditioners can make some patients more itchy.

CLDF has a leaflet on itch (pruritus).
What operations might be considered?

A number of operations have been tried in liver centres around the world in an attempt to reduce the effects of PFIC with varying degrees of success. The specialist team (medical and surgical) will make a careful assessment of your child’s/young person’s condition before any of these procedures are recommended.

These procedures are not appropriate in all cases.

- Partial external biliary diversion
  This is an operation which is only suitable in patients who have not developed cirrhosis. It is usually only considered when all medical treatments have failed to control the itch (pruritus).

  A short section of the child’s/young person’s bowel is used to make a channel for some of the bile to drain away. One end of it is attached to the gall bladder and the other end is brought out through the skin to form a stoma (surgically created opening) on the surface of the abdomen. An adhesive bag is worn over the stoma to collect the bile produced.

  The aim of this is to remove some bile and thus reduce the amount of bile acids re-entering the circulation, and thus reduce itching. This may, however, make malabsorption and vitamin deficiencies worse.

  Important body ‘salts’ may also be lost and may need to be replaced by taking additional medication.

- Internal ileal exclusion
  This is a different operation in which a bypass is created around the distal ileum, this is the section of bowel where bile salts are usually reabsorbed. The aim of this operation is also to reduce the amount of bile salts reabsorbed into the blood stream.

  Diarrhoea is a possible complication.

  Other supplements may be needed as the terminal ileum is also important in the absorption of other food elements.

- Liver transplant
  This is a major operation with some risks but a successful transplant can restore good quality of life. After a liver transplant children need to take anti-rejection medicines for the rest of their life, have regular medical follow-up and will be at some risk of side effects from the medicines. Liver transplantation is not suitable for all cases.

- Liver transplantation does not correct all the problems associated with a type of PFIC called FIC1 deficiency (see below); particularly diarrhoea and growth.

Why do children have PFIC?

PFIC is present at birth, although in some cases it will go undiagnosed for months or occasionally for years. A child’s ability to make the special proteins which control the way bile is made and excreted is inherited through the genes passed on from both parents. Genes are the instructions contained in the female egg and the male sperm which determine the colour of our skin, eyes, hair and many of our other physical characteristics. Genes in our body are in pairs, we inherit one of each pair from our mother and one from our father.

PFIC occurs when a baby inherits from both parents a gene which has the wrong instructions for bile formation or excretion. It may also be caused by a new mutation — this is when the parent(s) has/have a normal gene but as it is passed to the child it is changed so that it no longer carries the correct instructions. The particular genes involved in either case determine the type of PFIC the child/young person has.

The gene is called ATP8B1.
As with any inherited condition the chance of a child being affected is increased when the parents are consanguineous i.e. related other than by marriage, for example they are first cousins. Two-thirds of patients currently diagnosed with PFIC have parents who are not consanguineous.

**What is the chance of another child in the family having PFIC?**

In most cases if a couple have a child with PFIC any other children they have together will have:

- A one in four (25%) chance of having PFIC.
- A one in two (50%) chance of being a ‘carrier’, i.e. not affected but have one normal and one abnormal gene, like the parents.
- A one in four (25%) chance of being completely clear, i.e. have two normal genes.

**What are the different subgroups of PFIC?**

The list below sets out the most commonly recognised names for these conditions, and the glossary which follows gives the meaning of the initials used. Understanding and classification of this group of conditions is still developing and more subgroups are being identified.

- **FIC1 deficiency**
  Including PFIC and BRIC
  Previously called PFIC1 or Byler Disease (Byler was the name of one of the first families whose children were identified as having this condition).
  The gene is called *ATP8B1*.

- **BSEP deficiency**
  Previously known as PFIC2.
  The gene is called *ABCB11*.

- **MDR3 deficiency**
  Previously known as PFIC3.
  The gene is called *ABCB4*.

**Explanation of some terms used in this leaflet:**

- **Progressive** — the condition goes on getting worse
- **Familial** — transmitted via the genes down through generations (but may not have caused symptoms in previous generations)
- **Intrahepatic** — within the liver
- **Conjugated Bilirubin** — bilirubin which has been changed from the unconjugated form by being ‘processed’ in the liver
- **Cholestasis** — reduced bile flow
- **BRIC** — Benign Recurrent Intrahepatic Cholestasis
- **BSEP** — Bile Salt Export Pump
- **MDR3** — Multi-drug Resistance Protein 3 (name of protein)
- **NSC** — Neonatal Sclerosing Cholangitis
- **Sclerosing** — hardening, damaging process
- **Cholangitis** — inflammation of bile ducts

**How is the type of PFIC diagnosed?**

Even with information from a liver biopsy, it may be very difficult to distinguish PFIC from other types of liver disease in the newborn some of which resolve without specific treatment. It may only be the persisting nature of the jaundice and/or abnormal liver function tests over several months which indicates the possibility of PFIC. It takes even longer to try to determine the type of PFIC a child has.
The presentation of the different types can be very similar.

The GGT levels in the blood are low or normal in FIC1 and BSEP deficiencies but raised in MDR3 deficiency.

The only way to make a specific diagnosis is genetic testing. This is done by special blood tests from the child/young person and the parent(s) which usually take many months to be processed, it may also be helped by consulting a geneticist — someone who specialises in the way in which inherited conditions are passed down through family members.

SUMMARY OF CHARACTERISTICS OF THE DIFFERENT TYPES OF PFIC

FIC1 deficiency
This includes BRIC and PFIC which are now thought to be the same condition with different degrees of severity.

- Results from a defect in bile acid secretion which means bile is not formed properly
- Normal GGT (specific bile duct enzyme test) even if bilirubin level is high
- Presents with jaundice and pruritus
- High levels of serum bile acids
- Has a wide range of severity

Characteristics outside the liver
- Diarrhoea or loose stools is common
- Slower growth and short stature is common
- Pancreatitis (inflammation of the pancreas) has been associated in some cases
- Thicker skin
- Hearing problems

It is common for many of these characteristics to persist even after a successful liver transplant

Specific features of BRIC
- Recurrent episodes of symptoms which may be quite mild
- First sign is often itch (pruritus), jaundice may also occur
- First episode of symptoms can be at any age and may be precipitated by factors such as infection or medication
- Presentation at anything from 2 months to 47 years has been recorded
- Frequency and severity of episodes can vary greatly — once a year to once every ten years has been described, and generally reduce with age
- Duration of attacks can vary from several weeks to many months and in rare cases can even last for years
- Some patients with BRIC have no signs of liver damage even in old age and after many attacks. However, others can have slowly progressive liver disease

Specific features of PFIC
- May present in the first year of life with intense pruritus and some degree of itching
- Signs of fat-soluble vitamin deficiencies are common
- Progresses to chronic liver disease at varying rates and to varying degrees of severity
- Without any treatment liver disease is progressive leading to liver failure and death before adulthood

BRIC and PFIC are the two ends of the same spectrum and the disease can present anywhere in between.
Is there a charity taking action against the effects of childhood liver disease?
Yes. Started by families in 1980, Children's Liver Disease Foundation (CLDF) leads the way in fighting all childhood liver disease. CLDF funds vital research, develops information and awareness programmes and supports families, young people and adults diagnosed in childhood who are living day in, day out with a liver condition or transplant. And its work has made a big difference and continues to help save lives.

CLDF has so much to offer you: information, the opportunity to meet other families, events and regular updates. To find out more, call, email or write today: Children's Liver Disease Foundation, 36 Great Charles Street, Birmingham, B3 3JY 0121 212 3839
Main site: childliverdisease.org
Young people's site: cldf-focus.org
info@childliverdisease.org

What are the roles of CLDF's Family and Young People's teams?
CLDF's Family and Young People's teams are here for you, whether you want to talk about issues affecting you, meet and share with others or just belong to a group which cares, knows what it's like and is fighting to make a difference. You are not alone.

BSEP deficiency
- The BSEP protein is either absent or significantly reduced. GGT levels in the blood are normal
- This protein is responsible for moving bile acids out of the liver cell into the bile
- Fatty stools are common
- Pruritus becomes severe
- Growth is usually significantly slowed
- Cirrhosis often occurs before the age of 10 years
- Gall stones are common
- Generally have an excellent response to liver transplantation
- Milder forms have also been identified. There is a significant risk of liver cancer in this type of PFIC, this makes regular monitoring particularly important

MDR3 deficiency
- Caused by the absence or dysfunction of multidrug resistance protein 3 (MDR3)
- Characterised by markedly high levels of GGT in the blood — this is an important difference from FIC1 and BSEP deficiencies
- Low level of phospholipids (specific type of fat) in the bile. Phospholipids appear to have some protective function in the bile ducts
- Pruritus tends to be milder
- Bile duct damage may occur
- Gallstones are common in this type
- Higher risk of cholangitis
- High risk of portal hypertension
- Generally have an excellent response to liver transplantation
- There is a very wide range of severity

Other more recently recognised subgroups of PFIC include:

Neonatal Sclerosing Cholangitis (NSC)
- The gene responsible for this condition has not yet been identified
- It is associated with high GGT levels
- The presentation and symptoms are very similar to another liver disease found in babies called biliary atresia
- Fibrosis and cirrhosis are often progressive leading to deterioration of liver function and often liver transplant in childhood

Familial Hypercholanaemia
- Low GGT cholestasis
- Usually mild liver disease
- Experimental forms of treatment may be available soon

Aagenaes Syndrome
- Low GGT Cholestasis
- Associated with leg swelling (oedema)
- Mild liver disease

ARC Syndrome [Arthrogryphosis (bone abnormalities), Renal (kidney) dysfunction and Cholestasis]
- Often with many other abnormalities
It is expected that more subgroups will be identified in the future and that these will be better understood.

RESEARCH
Research continues in order to further the understanding of all types of PFIC and how it can best be controlled and treated.

Experimental treatments are being tried and evaluated to see what part they should play in the future management of children with PFIC.
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Our parents say . . .

“. . . We don’t know how we would have coped without CLDF’s care and support. They have been just fantastic from the outset — tremendous people, who are compassionate and so positive. They really care about families and children struggling with liver disease.”

“When Emily was very ill we felt we were on the sidelines, knowing we couldn’t influence the outcome and not in control. Getting involved in fundraising is something you can control and achieve a positive result. I really took comfort from that.”

Our young people say . . .

“Knowing CLDF is there is what I need. I can call whenever I want. Whatever I think and feel is listened to. Even when I called to tell them it was my birthday!”

“I feel really well. It’s great that CLDF has given us the chance to meet other young people outside of the hospital and have a fun time. I want them to do more things like this.”

Families Team
families@childliverdisease.org
0121 212 6023

Young People’s Team
youngpeople@childliverdisease.org
0121 212 6023
Donation, Regular Gift & Gift Aid Declaration Form

To make a one-off gift or set up a direct debit gift online, go to childliverdisease.org

I’d like to make a gift to CLDF

How much? £10 □ £20 □ Other £ ...............

☐ I enclose a cheque made payable to Children’s Liver Disease Foundation

☐ I wish to pay by card — MASTERCARD / VISA / DEBIT CARD (delete as appropriate)

Card No. □□□□ □□□□ □□□□ □□□□ Expiry Date ...... / ...... / ......

Name on Card ............................................. Security Number: ............. (back of card)

I’d like to make a regular gift by direct debit to CLDF

How much? £5 □ £10 □ £20 □ £25 □ £50 □ other £ ............

How often? ☐ monthly ☐ quarterly ☐ half-yearly ☐ annually

My bank details:

Bank name: ............................................. Branch name: .............................................

My bank address: ..................................................................................................................

.................................................................................................. Postcode: ............................

My bank sort code: □□ □□ □□ □□ My bank account number: ...........................................

Please pay to Children’s Liver Disease Foundation, account no. 00181442, sort code: 12-05-65

Starting on ...... / ...... / ...... until further notice. My signature: ............................................

Are you a UK taxpayer? Yes / No If yes, please give your gift under Gift Aid.

I confirm that I have paid or will pay an amount of Income tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or CASCs that I donate to will reclaim on my gifts for that year.

I understand that: the charity will reclaim 25p of tax on every £1 that I give, I may cancel this declaration at any time, and I must inform CLDF if I change my name and/or address whilst this declaration is in force. All gift aid details will be confirmed in your acknowledgement letter.

☐ Yes, please treat this and any future donations as given under gift aid. Date: ............

About you:

First name: .................................. Surname: .......................Title: Mr / Mrs / Ms / Miss / ...........

My address is: ..............................................................................................................................

.................................................................................................. Postcode: ............................

Home telephone: ........................................ Mobile: ............................................................

Home email: ............................................... Work email: ......................................................

To claim gift aid we are required to have your full name and address including postcode.

Please return your completed form to CLDF, address below. Thank you.

Children’s Liver Disease Foundation, 36 Great Charles Street, Birmingham B3 3JY
Children’s Liver Disease Foundation is the UK’s leading organisation dedicated to taking action against the effects of childhood liver disease.

It provides free of charge:

- A huge selection of literature and online animations on the working of the liver available in print and online
- Information packs for a wide range of audiences, including young people, parents/carers, GP practices, schools and nurseries, friends and relatives
- Families and young people’s teams providing services in person, online, facebook, text and phone
- Developing services for adults diagnosed with a liver disease in childhood
- Website – childliverdisease.org
- Young people’s website – cldf-focus.org
- National event programme for families and young people to meet, share and have fun
- Secure online message board – childliverdisease.org/forum

Around 75% of CLDF’s annual income is derived from voluntary donations. Please help us to continue to support young people, families and adults diagnosed in childhood by making a donation. You can do this online or by completing the donation form in this leaflet. Even better, a regular direct debit gift will enable us to plan our work more fully.

Thank you.

Children’s Liver Disease Foundation
36 Great Charles Street
Birmingham
B3 3JY

0121 212 3839 info@childliverdisease.org

/CLDFonline  @tweetCLDF