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GUIDELINES

for families with a child with heart disease

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**Federal association
for children with
heart disease**



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For reasons of readability only the male form is used, when addressing people, such as doctors or educators. Of course, this refers equally to both women and men.

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Heart defect? We help!

Dear parents,

In Germany, between 6,000 and 8,000 children are born with heart problems every year. Congenital heart defects, which occur at a rate of almost 1 percent, are the most frequent congenital defects and their causes are “multifactorial”, i.e. they are caused by several different factors operating together. The type and degree of the many different heart defects vary greatly, related illnesses progress in various ways, and there is often more than one treatment option available.



If your child has been born with a heart defect, you still can welcome the baby with optimism! This child may be different to what you imagined during pregnancy, but it has good prospects of leading a largely normal life, if perhaps with the help of medicine and with some restrictions. Many of “our” families have already gone through this experience and will be happy to share with you what they’ve learned.

The birth of a child with a heart defect sets the entire “family mobile” in motion and all family members usually need support. We and our regional parents’ initiatives are glad to help. Thanks to medical progress, increasing numbers of children with heart defects, who might have died 20 years ago, now live to become adults. Many of them will rely all their lives on a tightly-interwoven system of care, which requires good, confident communication between children, family doctors, therapists, kindergarten and school teachers and the family. You are the mediator between your child and the doctors, carers and teachers. Have all necessary treatments explained to you in a way that you can understand, several times if necessary, and ask about what is import-

ant in everyday life with your child. Don’t just accept experts’ jargon and ask more questions if there’s something you don’t understand.

To cope with fear, one needs not only courage, but also information. This brochure is designed to serve as a guide and to inform you about the meaning of and prognosis for a child with a heart defect, and about the criteria involved in choosing a hospital. It contains tips for kindergarten, school, sport, rehabilitation and much more. However, the brochure cannot take the place of an open discussion with the people looking after your child together with you. We will be happy to support you.

Hermine Nock

Bundesverband Herzkranke Kinder e.V. (BVHK)



1. The heart: seat of the soul or just a pump?

The heart is a special organ and is associated with emotions and the soul. In other cultures the heart is also of central importance. Islamic Sufis developed a proper science of the heart. In Sufism, the heart was regarded as the organ of sensual and spiritual perception. This was also expressed in Arabic poetry. Arabic literature often depicts flaming hearts, which are described as having been inspired by Allah.

This wider significance can mean that congenital heart disease is perceived as something very ominous. Children understand the vital function of their heart from a very young age and may react with fear if there's something wrong with it.

Many well-known old sayings depict emotional significance of the heart in vivid metaphors:

Don't lose heart!

My heart is breaking.

It is only with the heart that one can see rightly.

(Antoine de Saint-Exupery)



2. Causes of congenital heart disease (CHD). Why us?

Embryonic development of the heart occurs in the first weeks of pregnancy and is very complex. Difficulties can emerge at any point in this development and lead to heart abnormalities at a later stage. The causes of congenital heart disease have not yet been extensively researched and involve a still unexplained combination of various factors. Expectant mothers often don't even know they are pregnant while these developments are taking place.“



Many parents are later burdened by feelings of guilt, although in most cases there is nothing they could have done to avoid the emergence of heart disease, so the search for causes or blame for the illness is futile. We encourage you to actively embrace your child's disease and look to the future.

In Germany around 22 children are born with CHD every day. After the nerve-wracking acute phase is over, most families manage to achieve a good quality of life. The best way to help your child is to take the most positive attitude possible.





3. How do we recognise that our child has heart disease?



Sometimes heart disease is detected by a gynaecologist before birth, but not all heart diseases can be prenatally diagnosed. Gynaecologists need plenty of experience and good technical equipment to do this. Your doctor should then hold extensive consultations with a paediatric cardiologist so that you can find out which treatments may be necessary after your child's birth and how they can perhaps be best prepared for.

If you are deciding whether to continue or terminate the pregnancy, you should consult other professionals as well as your doctor. There are psycho-social information centres and self-help organisations in your local area that will help you understand your options. No one is more insightful about the everyday life of a family with a child with heart disease than parents who have lived for a long time with such a child. Our brochure on „Prenatal Diagnosis“ provides lots of useful information on this subject. You will also find descriptions of heart diseases and treatments, written in a generally comprehensible style, at www.corience.org.



If a heart murmur is detected in your child after birth, you should be referred to a hospital specialising in congenital heart disease. It's often hard to tell whether babies are suffering from a congenital heart condition just by looking at them. They may be short of breath or not drinking enough, but not all of them have blue lips and fingernails.

Only cyanotic newborns („blue babies“), whose heart defect causes oxygen-deficient blood to circulate through the body, are conspicuous by their bluish skin colour (cyanosis = „blue baby syndrome“). As parents, you will be able to assess your child well and will quickly notice if something is wrong. Talk to your doctor or a nurse if you are uncertain.

4. What does heart disease mean for our child?



There are a number of different congenital heart defects of varying degrees of seriousness and they may occur in combination with other syndromes. They are divided into four groups:

- ♥ Narrowings/Closures
- ♥ Cardiac septum disorders (holes)
- ♥ Connective dysfunctions and
- ♥ Valve insufficiencies (valves cannot (fully) function)

Heart defects are however all different from one another and disease will progress differently from one patient to the next. Each treatment also takes an individual path. Whether your child needs medication, a cardiac catheter implant (with a thin plastic tube inserted into the heart or blood vessels via the groin, for example) or a heart operation will depend on many factors.





Children with minor heart defects, such as irregular walls between the atria or ventricles, have good prospects of leading an almost normal life after a successful heart operation. Thanks to medical progress, the prognosis (outlook) is good for patients undergoing procedures that were unimaginable 10-20 years ago. For this reason however, there are still few long-term results available.

Children with severe heart defects or an unfavourable progression of their disease will have to cope with major limitations to their physical capacity. Your paediatric cardiologist can give you more precise information.



5. What's the prognosis for our child?

A child's chances of survival, quality of life, and physical and mental development are influenced by many different factors. Some children with congenital heart defects develop slowly, while others experience lasting developmental disorders or difficulties in concentrating. Most of them can go to regular schools with few limitations, and play sports, travel and lead largely normal everyday lives with a modified lifestyle.



Many congenital heart defects cannot be completely corrected, rather, the effects can be mitigated (although the heart does not function normally, symptoms can be relieved, which can be the best possible way of managing the disease).

Feeding the child, especially a very young child, can often be problematic. Feeding tubes may be necessary and breastfeeding may only be possible after initial difficulties. Some children with heart defects who contract the usual childhood illnesses will need especially careful treatment by a qualified paediatric cardiologist. Children's medication (i.e. to inhibit blood-clotting) must be administered regularly in exact doses and athletic activities may have to be limited. „Harmless“ dental treatments or similar procedures may require endocardial prophylaxis (medicine to prevent inflammation of the heart's inner membrane).



Several vaccines are particularly recommended for children with heart disease, who are classified as high-risk patients. Your paediatric cardiologist will inform you about such treatments. Questions about kindergarten, school (regular or special-needs), and later career prospects, etc. are discussed in points 13 and 14.1.

You should talk about issues such as the best time for a necessary operation, whether it will involve open-heart surgery or whether a hole could be closed by inserting a catheter, and what the advantages and disadvantages of the various methods are, with your paediatric cardio-



logist or heart surgeon. If you're in doubt, we can put you in touch with an appropriate contact person and support you in finding a hospital to suit your needs.

6. What if my child has another illness as well as heart disease?

Congenital heart disease is often accompanied by other syndromes such as Williams syndrome, Marfan syndrome or Down's syndrome. Detailed medical information on this topic can be found at www.corience.org. Syndromes, often mean that specific symptoms



occur together. Early, holistic support is important for children whose mental and physical development is impacted. This support can be offered in a socialpaediatric centre or a special needs facility for young children for example, where various therapies can be provided in a playful environment.

7. Who can help us evaluate the risks?

If your child needs treatment or a heart operation, ask your paediatric cardiologist which hospital he or she recommends. Before this decision is taken, a comprehensive diagnosis and careful evaluation of potential treatments and their risks will be made. It may seem extremely difficult to agree to an operation when your child is in good physical condition, but you need to focus on the child's long-term prognosis. Your choice of hospital should not be dictated by external factors only (such as ease of accessibility and the appearance of the ward), but by the expertise of the treatment team. Self-help groups for those with congenital heart disease and the BVHK will be able to give you more information.

As a general rule, if you don't understand everything, ask for an interpreter to translate into your native language (there may be a doctor or nurse on staff who also comes from your country, for example).



8. What's important in choosing a hospital?

A heart operation will be followed by a long stay in hospital for your child. Choose a hospital that specialises in treating congenital heart disease. It is possible that it will be far away from where you live. If you are accompanying your child, find out well in advance where you as parents will be able to stay overnight. Apply early to your health insurer to claim benefits such as accommodation for an accompanying adult, travel costs, and home help for your other children. Take advantage of the information provided by the hospital or ask a psycho-social professional.



8.1 Help with all questions



Medical consultation sessions are often hard to understand and may cause anxiety, because the doctor must explain all the potential complications, even if these occur only in extreme cases. Don't be shy about asking someone to accompany you to this meeting. In such stressful situations, it's not unusual to be unable to properly take in large amounts of information and to not remember much of it later

on. Take note of anything you did not understand and make a list of your questions for the next discussion.



8.2 How can we erase any doubts we may have?

If you still have doubts about the proposed treatment despite the detailed explanations and information provided, you can seek a second opinion at another paediatric heart centre. Addresses can be obtained from your paediatric cardiologist, or ask us. You are also entitled to access your child's medical records, should you so desire.

9. What must we resolve before going to hospital for treatment?

- ♥ Organise accommodation for the accompanying adult (there is a right to admittance for one parent accompanying a child aged under 6 or in case of medical necessity as certified by a doctor)
- ♥ Arrange home help for your other children
- ♥ Apply to your health insurer for home help and travel costs
- ♥ Request time off from your employer
- ♥ Make a list of all the questions you may have

10. What's in store for us in hospital?

The heart operation, stay in the children's clinic, and the fixed daily routine of a hospital is an unusual situation for you. Visits, examinations, shift changes, discussions and tests involving various professionals often cannot be coordinated to suit you. You may sometimes find yourself at awkward times in the presence of your child and other „listeners“ whom you may not feel comfortable with. The daily task of the team of doctors and nurses is to provide the best possible medical and nursing care for patients. Please be aware that not all your relatives may be able to visit your child. Younger siblings are often not admitted to wards for reasons of hygiene. Because patients are gravely ill and at high risk of infection, especially in the intensive care unit, it's important that you're accompanied only by your closest relatives.





10.1 Mutual consideration is required

The doctors and nurses are familiar with the strong emotions of patients and their families, such as fear, gratitude, helplessness, happiness,



anger and sorrow. Nevertheless, mutual understanding and consideration for the hospital's daily routine and the staff's heavy workload will help everyone achieve a trusting and confident coexistence. You will have to relinquish a large amount of the responsibility for your child in hospital. Although it may be difficult, while your child is in hospital, others will predominantly decide what's best. Consider yourself part of the nursing team. Your

cooperation will support their work and contribute to your child's well-being. Ask the nursing staff if you have doubts or concerns and have them show and explain everything to you precisely. Repeat your questions several times if you need to, even if they seem banal. Most clinics offer psycho-social services or a case manager to support you during outpatient treatment after your child is released.

A visit to the zoo with grandma or a weekend spent with kids their own age may make up for any deprivations. Family-Oriented Rehabilitation (FOR) can also give the family new orientation and strength when the child comes home from hospital.

10.3 What should we pack?



- ♥ Pyjamas (preferably with buttons)
- ♥ A tracksuit
- ♥ Toy animals etc.
- ♥ Shirts (preferably with buttons)
- ♥ Warm socks
- ♥ Light, comfortable clothing
- ♥ Toiletries
- ♥ For recreation: favourite books, paints, crayons, pencils, puzzle books, educational games, a Discman, CD or MP3 player with stories or music, video tapes or DVDs with headphones
- ♥ Toys suitable for hospital, which won't fall through the bars on the bed, for example



10.2 Who will look after the siblings?

In specific circumstances, you can apply for home help for children under the age of 14. Psycho-social services professionals at the hospital or our social welfare hotline can inform you about options for financing sibling home care and help you to apply for nursing insurance or severely-disabled status. Don't forget also, that the siblings of your sick child often have more vague fears than the adults. The „big people“ are preoccupied and hardly have the time and energy to notice their other children's worries and fantasies. These „shadow children“ sometimes feel neglected and experience setbacks in their development. Try to find replacement supervision to cover the time you need to spend with your sick child or for your own recovery.





10.4 What does our child need from us now?

Don't tell your child well-meaning lies. Children can cope with the truth better than we think. How will the child be able to trust you if you trivialise or say nothing at all about a possibly painful medical procedure or a long stay in hospital? The closer you can be to your child during this difficult time, the better. Your child's fears will be soothed if you accompany him to tests, comfort him, distract him and help him express his wishes. If you feed him, wash him, tell him something

or sing with him, you respect his frightening thoughts and strengthen his self-confidence and feeling of self-worth. This will also help you to quickly overcome any feelings of helplessness. Devout families often find comfort in prayer and pass this strength on to their children.

10.5 What can help us through this difficult time?

Take care of yourself. If your child is feeling well, he or she will make friends with roommates in the ward, take part in games with hospital staff and manage for an hour or so without you. Take some time out for yourself! Don't overestimate your own strength. Rest, go for a walk in the park or go home and see the rest of your family if you need to.



The more relaxed and stable the parents are, the calmer the child will feel. Because the reverse is also true and your stress is passed on to the child, it is important that you look after yourself especially well during this time.

Nobody is helped when your batteries get run down and aren't recharged in time. Not you and certainly not your child.

11. What happens after admission to hospital?

Your child will be examined and you will probably be asked about any illnesses in the family and the course of the child's illness so far. Documents given to you by the referring doctor and notes on previous examinations should be in your child's medical file. Since this is not always the case, it is advisable to bring copies of the last doctor's letter, vaccination card, 'Herzpass' (heart disease record card) etc. as a precaution.



Before the heart operation there will be a medical briefing, normally held with the paediatric cardiac surgeon, the paediatric cardiologist and the anaesthetist (who is responsible for anaesthesia).

11.1 Prepare medical briefings well

You should prepare for this, by noting dates of any previous procedures for example, because you will have to sign a declaration of consent for the operation. Request an interpreter to translate into your native language if you need one. Consider in advance whether your child should be at this medical briefing. If you decide against this, ask someone you trust to look after the child during this time so that you will be able to concentrate fully and completely on this important discussion. Both parents should be present if at all possible. Ask how long the operation will approximately take but don't worry if it takes longer.



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11.2 How does the heart operation proceed?



This is a day of both fear and hope, which will understandably give rise to a range of very diverse feelings in you. The moment of parting outside the operating theatre is a very emotional one for you and your child. If you cannot or do not want to accompany your child to that point, it is perfectly alright for you to take leave of your child earlier. In this difficult moment, try to give your child confidence. Your calm will support and strengthen your child. You could give your child a familiar object that he or she will recognise upon waking up, such as a toy animal or a dummy.

Try to distract yourself and not wait the whole time in the ward. Cooperate with the hospital doctors and comply with their rules and requests.



The anaesthetist's request that the child be given nothing to eat before the operation is not made to annoy you or your child. Do not give your child anything to drink or eat out of pity, even if it disrupts your schedule, because doing so could lead to complications during the anaesthetic.

In our brochure on "Preparing for a heart operation" you will find precise information about various routine examinations,

the progress of the operation, and especially about the time spent in the intensive care ward.

© Prof. Ehrenfried Schindler

12. What happens when the child comes home from hospital?

Having a good paediatric cardiologist near your home will be helpful, because your child will need to go for regular checkups. Various ambulant therapies may be suggested and you must decide whether these are all reasonable and necessary or just an added burden on an already full daily schedule. Exchanging ideas and experiences in a local self-help group can also be extremely helpful.



The group should also be able to explain to you other aspects such as social security assistance, severe disability, nursing care insurance, household help, and FOR. You can find the addresses on page 30-31 or at www.bvhk.de.

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13. What's important in choosing a kindergarten?



Most children with heart conditions can attend a normal kindergarten with their siblings and friends. To obtain a place in a kindergarten for severely restricted children or those requiring high levels of care and attention, it is helpful to have your doctor write a letter stating that the child has "special educational needs". This will enable your child to receive optimal support in an appropriate facility (integrative kindergarten or day care centre for disabled and non-disabled children) from specially-trained staff, usually specialist remedial teachers.

Any required therapies (ergotherapy, physiotherapy, logopaedia) can then also usually be carried out at kindergarten, which is a great relief for you and frees up time for normal everyday life. Psycho-social services staff in the hospital or your social-paediatric centre (SPZ) will help you decide whether a kindergarten near your home or a special facility



further away would be better for your child. For example, you could apply for transport to a more distant child care centre so that you will not have to spend hours every day transporting your child to and from kindergarten.

You should make it clear that your child should not receive any special



treatment in kindergarten or at school. Be open about your child's heart condition and do not conceal or trivialise your child's limitations or needs. If the teachers and children in the group know that special care must be taken when wrestling, for example, and that your child may need more rests, they will deal with your child in a fair and natural way. Regular and honest discussions will make it easier for everyone to strike a balance

between anxiety and a relaxed, cheerful relationship with your child.

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Important!

Inform kindergarten teachers early on about your child's medication and its possible effects: see the chapter on "Medication". s. page 27-29.

Well-informed staff in the kindergarten will not be flustered or panic and will be well-versed in first-aid procedures.

14. What about when the child starts school?

There are many and various kinds of schools offering different curricula and support options, depending on which federal state they're in. Our 'School/ Careers' working group has compiled a list of contact centres and support options for you at www.bvhk.de. A special school further from home may represent a good opportunity for your child to have his talents supported appropriately. The high studentteacher ratio and good financial resources in these schools mean that speciallytrained teachers can cater to your child's needs, which may not always be possible in ordinary local schools.



14.1 Inform the teachers

In choosing a school, however, you must realise that the child's friends in your neighbourhood will usually go to the school "around the corner" and maintaining social contacts in a special school further away will involve more time and effort. Be open about your child's heart condition and inform people of it in advance. Do not conceal or trivialise your child's limitations or needs so that teachers can deal with them appropriately.



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Schoolchildren requiring long stays in hospital can be either taught in hospital in a “school for sick children” or the child’s regular school can pass on materials to the child in hospital. Visits from fellow pupils are also helpful for the sick children and ensure that they don’t lose contact with their school.



14.2 School trips, exchange programmes etc.

When planning events and excursions outside the school, teachers need to know whether your child has to take medication regularly and which ones. If your child can do this independently and reliably at home, he or she will not need the teacher’s help. If the teacher will have to remind or otherwise support your child in taking medication, inform the teacher early on before the excursion. Pack the medication in individual packages that are labelled so that your child knows whether or not he or she has already taken the daily ration. Children suffering from oxygen deficiency should not go to mountainous areas (higher than 1,000 metres above sea level). Please consult your paediatric cardiologist if plane trips are planned.

Exciting activities (e.g. roller coasters) are too risky for some children with heart conditions.

Long hikes, physically tiring activities and types of sports in which they are likely to be injured are not appropriate for children whose heart condition means that their activities are restricted. Using a little imagination and consideration will enable these children to take part in shared excursions; small individual adjustments are often enough.



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14.3 School sport

Children with heart conditions are sometimes kept from sport for their own protection, although this often causes them to be uncertain and awkward and to develop motor skills deficits. In our “Sport macht stark” (sport makes you strong) brochure: www.bvhk.de you will find valuable information about which sport is appropriate for children with which heart condition.



Swimming lessons in mixed classes are not permitted for observant Muslim children, but many Islamic centres offer swimming for Islamic families as an alternative.

Very competitive and combat sports are taboo for many children with heart conditions. Dedicated teachers can involve and assess children with complex heart conditions in a different way and allow them to rest when they need to. Pupils with cardiac arrhythmia (long QT syndrome) in particular and those with serious chronic oxygen deficiency (cyanosis) should be precisely informed by their paediatric cardiologist and by you about what to do if their heart is racing (go somewhere quiet, normalise the heartbeat with deep breathing) or stumbles.



14.4 Integrating into the class

The simple assistance methods described above will make it easier for your child to find and maintain “his place” in the class:

- Having a second set of books could help a physically restricted child who has to move to different classrooms on various floors.
- If it’s hard for your child to climb stairs, could the child use a stair lift?
- Special conditions in tests (e.g. more time, different sport activities) can be arranged for children who find it hard to concentrate or are simply slower.
- Many schools offer Ethics instead of Religion as an alternative



subject for children of other religions.

- e) During the high religious holidays of other cultures, the child could be freed from classes. Speak to the class teacher/school principal in advance.
- f) Individual solutions can be sought for religious rituals, e.g. fasting during Ramadan, when observant Muslims may not eat or drink between sunrise and sunset. Children do not have to fast before puberty, nor is it necessary if it will endanger the person's health or if he or she is chronically ill and, for example, relies on medication. Acutely ill Muslims are exempted from fasting.
- g) Make sure in advance that your child and yourself are provided with the opportunity to conduct prayers as required.
- h) Our "School/Careers" and "Kindergarten" working groups have more information for you at www.bvhk.de.



14.5 Bullying

Children with heart conditions whose activities are restricted and who may stand out because of scars, scoliosis (spinal curvature), blue lips or so-called 'hourglass nails' are sometimes teased by insensitive classmates. If your child comes home from school listless over a long period or is unusually silent, find out whether the child is being bullied. If the child is being bullied you should get help from teachers immediately, because bullying can put a great strain on your child. However, it will not be possible to prevent some classmates from envying your child because of "special treatment in sport" or different test conditions due to concentration problems.

Providing open, honest information and holding personal discussions, including with the parents of the "bullies", will in most cases help to create understanding and even a sense of responsibility among classmates. They may then even volunteer to carry a heavy schoolbag or help with homework.



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15. Medication

- ♥ Children who have to take diuretic medications need to go to the toilet frequently. Please inform your child's teachers so that they can develop appropriate rules for the class and your child.
- ♥ Children who rely on beta blockers (to reduce pulse rate and blood pressure) often have problems concentrating. Teachers should take this into consideration during crafts and other activities, as well as in assessment.
- ♥ Children for whom anticoagulants (blood-thinning medicines) have been prescribed are at great risk of blood loss or internal bleeding from even slight injuries. This risk must be taken into account during romping play, exercise and other physical activities (school sport). The other children should also be aware of this and take appropriate care. If a fall or other injury occurs, the teacher should inform you immediately and obtain immediate medical treatment. Supervisory staff must be aware of the fatal consequences that a disruption in the intake of blood-thinning medication could have.
- ♥ You as parents can give your child much more freedom and scope for activity if you and the child together start carrying out INR self-monitoring (measuring blood coagulation levels) using a so-called 'coaguchek' device. Your health insurance fund will pay for this device if your doctor has made an application and you have received a referral. Your child can then measure the levels alone and determine whether and how much Marcumar® (or other blood-thinning medicine) is necessary.





- ♥ Children who have had heart transplants must be given their medication with particular reliability and regularity, especially immunosuppressants (which suppress rejection of the donor heart). Inform teachers how vital these medicines and scrupulous compliance with hygiene regulations are. For example, if there is a gastrointestinal virus circulating in the class, parents of children with heart transplants should be informed and medical advice should be obtained.
- ♥ You also need to explain your child's nutritional requirements to teachers, i.e. if the child is not allowed to eat certain foods.
- ♥ Schoolchildren with arrhythmia should be precisely informed by their paediatric cardiologist and by you about what to do if their heart is racing (go somewhere quiet, normalise the heartbeat with deep breathing) or stumbles

Inform teachers early on about your child's medications and their possible side effects. A detailed, easy-to-understand letter from the child's doctor and a set of instructions about what to do in case of emergency, kept sealed in an envelope in a place known to all teachers, will give teachers and parents a feeling of security.

Leave your mobile phone number with the school so that you can be contacted if your child has an accident, an episode of arrhythmia or other unforeseeable occurrences. It is your duty as parents to cooperate faithfully in your child's school education.

Approach fearful, over-cautious teachers and talk to insensitive teachers. If you feel unable to do this for reasons to do with language, ask the parents' representative or your paediatrician / paediatric cardiologist for help. In the latter case you will have to release them from their obligation to maintain medical confidentiality. Open, intensive cooperation and the provision of precise information will help the kindergarten/school, your child, and you to enjoy a relaxed and successful kindergarten and school experience.



16. Rehabilitation

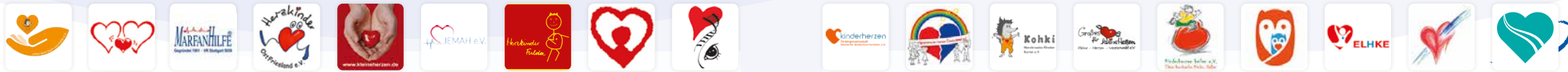
We have been campaigning for many years for FOR (Family Oriented Rehabilitation, i.e. aftercare). FOR involves all family members being admitted as inpatients to a rehab clinic to ensure that medical treatment is successful, to establish ongoing medication therapy, and to improve the physical abilities and strengthen the body and soul of both the sick child and the family. If as a family you can no longer ensure successful medical treatment, can no longer provide the sick child with sufficient support, or if one or more of your family members has experienced medical and psycho-social complications due to the child's illness, we would advise you to take advantage of FOR.



It is especially important for sick children to grow up in the best possible family environment, as this also promotes the healing process. Often, however, the parents' relationship is adversely affected by this permanent burden. Many couples separate after a while because they are unable to devote themselves sufficiently to their own intimate relationship and regard other issues as more important. Here they learn to come together again and see their partner with new eyes.

Order our FOR brochure, phone our social welfare hotline, or ask for more information at the psychosocial services centre in your hospital.





Adresses Your local contact

Herz-Kinder-Hilfe Hamburg e. V.

c/o Inge Heyde
Wolsteinkamp 63 - 22607 Hamburg
Tel. 040-82 29 38 81
i.heyde@herz-kinder-hilfe.de
www.herz-kinder-hilfe.de

Marfan Hilfe (Deutschland) e.V.

Postfach 0145 - 23691 Eutin
Tel. 0800 - 76 13 34 4
kontakt@marfanhilfe.de
www.marfan.de

Herzkinder Ostfriesland e. V.

c/o Jörg Rüterjans
Suurleegdenweg 5 - 26607 Aurich
Tel. 04941-60 44 316
info@herzkinder-ostfriesland.de
www.herzkinder-ostfriesland.de

Kleine Herzen Hannover e.V.

Hilfe für kranke Kinderherzen
c/o Ira Thorsting
Wirringer Str. 21a - 31319 Sehnde
Tel. 0 179-50 97 103
ira.thorsting@t-online.de
www.kleineherzen.de

JEMAH e.V. Bundesverein Jugendliche und Erwachsene mit angeborenem Herzfehler e.V.

Am Exer 19a - 38302 Wolfenbüttel
Tel. 05331-92 78 48 50
info@jemah.de
www.jemah.de

Aktion Kinderherz e. V. Düsseldorf

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aktionkinderherz@arcor.de
www.aktionkinderherz.de

Noonan-Kinder e.V. Deutschland

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Elterninitiative herzkranker Kinder Dortmund / Kreis Unna e.V.

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www.herzkinder-dortmund.de

Herzkinder Oberhausen und Umgebung e.V.

c/o Andrea Ruprecht
Babcockallee 7 - 46049 Oberhausen
Tel. 0176-72 38 80 48
herzkinder-oberhausen@t-online.de

Herzkranke Kinder e. V.

c/o Julia Ensel-Eckerth
Pottkamp 19 - 48149 Münster
Tel. 0251-85 70 43 57
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www.herzkranke-kinder-muenster.de

Fördermitglied im BVHK

Herzpfaster Coesfeld / Bunter Kreis Münsterland e.V.

c/o Johanna Kemper
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herzpfaster@bunter-kreis-coesfeld.de
johanna.kemper@bunter-kreis-coesfeld.de

Kinderherzhilfe Vechta e.V.

c/o Corinna Krogmann
Sonnenblumenweg 12 - 49377 Vechta
Tel. 04441-15 99 638
info@Kinderherzhilfe-Vechta.de
www.kinderherzhilfe-vechta.de

Elterninitiative herzkranker Kinder, Köln e.V.

c/o Ute Braun-Ehrenpreis
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Tel. 02171-55 86 92
info@herzkranke-kinder-koeln.de
www.herzkranke-kinder-koeln.de

Herzkrankes Kind Aachen e. V.

c/o Jörg Däsler
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Tel. 0241-99 74 10 74
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Elterninitiative herzkranker Kinder und Jugendlicher Bonn e.V.

c/o Christian Behre
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vorstand@herzkinder-bonn.de
www.herzkinder-bonn.de

Kinderherzen-Fördergemeinschaft Deutsche Kinderherzzentren e.V.

c/o Jörg Gattenlöhner
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Tel. 0228 422 800
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Hypoplastische Herzen Deutschland e.V.

c/o Birgit Höveler
Elisenstr. 12 - 53859 Niederkassel
Tel. 02208-77 00 33
b.hoeveler@hhdev.eu
www.hypoplastische-herzen-deutschland.de

Herzkranke Kinder Kohki e.V.

c/o Sigrud Schröder
Westring 241 - 55120 Mainz
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www.kohki.de

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Pumpis für Herzis

Kleine Herzen Westerwald e.V.

c/o Günter Mies
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Kinderherzen heilen e.V. - Eltern herzkranker Kinder - Gießen

c/o Ruth Knab
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kontakt@kinderherzen-heilen.de
www.kinderherzen-heilen.de

Herzkrankes Kind Homburg/Saar e.V.

c/o Dr. jur. Alexandra Windsberger
Universitätsklinik des Saarlandes - Gebäude 33
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66421 Homburg
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info@herzkrankes-kind-homburg.de
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Elterninitiative Herzkranker Kinder e. V., Tübingen, (ELHKE)

c/o Mita Ettischer
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Herzkinder Unterland e. V.

c/o Heidi Tilgner-Stahl.
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vorstand@herzkinder-unterland.de
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c/o Petra Huth -Geschäftsstelle-
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Junge Herzen Bayern

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ARVC-Selbsthilfe e.V.

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**Information brochure
Guidelines for families with a child with
heart disease**

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