
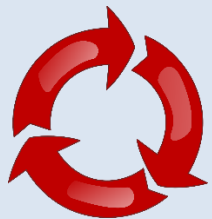



Timeline	Before birth	Birth	Life time	End of life	After death
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Journey stage	Timeline	Symptoms	Patient needs	Family/member/friends needs	Ideal outcome/support
Pregnancy	Before birth	<ol style="list-style-type: none"> 1. Abnormalities during ultrasound. 	Not applicable.	<ol style="list-style-type: none"> 1. Psychological support parent(s). 2. Special needs mother during pregnancy. 	<ol style="list-style-type: none"> 1. No complications during pregnancy. 2. Good/healthy prognosis for child after birth. 3. Psychological support parent(s).
Birth and diagnosis 	Birth	<ol style="list-style-type: none"> 1. Blue/purple markings on skin. 2. Color varies due to cold, heat, anxiety. 3. Asymmetric limbs (length and/or circumference). 4. Asymmetric kidneys. 5. Abnormal liver (eg. with cysts). 6. Other organ issues. 7. Intestines issues. 	<ol style="list-style-type: none"> 1. As soon as possible the right diagnosis. 2. Being referred to right medical expertise center. 3. Priority referral to multidisciplinary team. 4. Clinical practice guidelines. 	<ol style="list-style-type: none"> 1. Psychological support parent(s), siblings, grandparents and friends. 2. Contact with patient support group. 3. Access to appropriate, reliable and understandable information on the disease and peer & organisation support. 4. Treatment plan short term and long term. 	<ol style="list-style-type: none"> 1. The right medical diagnosis at once and quickly. 2. Timely access to the right expertise center and medical specialists. 3. Timely access to psychological support for family members. 4. Information material available. 5. Facilitate direct contact with the patient organisation for contact with other

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		8. Brain abnormalities (MRI).			patients/families, support and the latest information.
Symptoms 	Lifetime	Depending on the locations of the markings.	<ol style="list-style-type: none"> 1. Medically understanding what are the risks for mental retardation, glaucoma, consequences of high fluid pressure in brain, abnormal veins in the brain, etc. 2. Psychologically. These markings could be visible which could cause a lower self esteem, self image, etc. How to deal with this? 3. Psychosocially. Reactions of other people, in class, at work, etc. How to deal with this? Can patient participate (fully) in school, work, sport, relationships, etc.? If not this could cause social isolation. 	<ol style="list-style-type: none"> 1. Psychological support for parent(s), siblings, grandparents and friends. How to deal with strange looks from other people. How to deal with uncertainty. How to explain to other people. Impact on relationship parents. 2. Time management and practical organisation at home, school, work, etc. eg. when parent(s) need(s) to go to hospital with patient. 	<ol style="list-style-type: none"> 1. Knowing where to get and have access to the right medical treatment (might be outside own country). 2. Knowing where to get psychological and psychosocial support. 3. Having contact with other patients and families who have experienced something similar. 4. School inclusion programs to inform and facilitate the integration of the children living with the disease and training for teachers to reduce resistance and prejudice when teaching these children. 5. Living life to the fullest.

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					6. Minimum/no impact on other family members esp. siblings. 7. Balance at home between care and daily life.
Treatment 	Lifetime	1. Slow wound healing. 2. Open wounds. 3. Eye issues (glaucoma). 4. Brain malformation. 5. High fluid pressure brain. 6. Asymmetric limbs. 7. Lung issues (eg. pulmonary hypertension). 8. Kidney issues. 9. Liver issues. 10. Intestine issues. 11. Ear issues.	1. Multidisciplinary team. 2. Understanding the treatment options. 3. Identifying where is the best treatment available (it could be outside own country). 4. Understanding what are the risks (short and long term). 5. Good awareness about the patients do's and don'ts regarding the disease. 6. What is the impact on my future regarding, school, work, relationships, heredity of the disease, etc.?	1. Right medical expert treating the patient. 2. Financial support in case costs of diagnosis/treatment cannot be reimbursed. 3. Psychological support parent(s), family and friends.	1. Transfer from child care to adult care is planned and done in a smooth way. 2. Timely access to the right expertise center and medical specialists. Paediatric medical specialists available ('a child is not a young adult'). 3. Timely access to psychological support of the patient and family members. 4. Living life to the fullest. 5. Having all medical data in one place under control of the patient and/or parents.

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		12. Teeth issues. 13. Lymph issues. 14. Varicose veins. 15. Psychological issues. 16. Psychosocial issues. 17. Mental retardation.	7. Psychological support. 8. Psychosocial support. 9. Long term support (also when patient lives independently).		6. Minimum/no impact on other family members esp. siblings. 7. Balance at home between care and daily life.
Laser treatment	Lifetime	Visible veins.	1. The patient might want to remove the visible veins for aesthetic purposes. 2. With very young patients this could be a problem of the parents and not the child. 3. Local anaesthesia is required and very young children need a total anaesthesia. 4. Being informed well about risks (eg. scars, pigment changes, bleedings, infections)	1. Do the parents request laser treatment or is this the decision of the patient? 2. Psychological support parent(s), family and friends. 3. Being informed well about risks (eg. scars, pigment changes, bleedings, infections) both on short as well as long term. 4. Being well informed about the expected results both on short and long term. The effect on the face is normally better than on the legs.	1. The markings become less visible, no scars and no pigment damage. 2. The treatment is started at the right age. 3. The treatment is requested by the patient as much as possible. 4. Anaesthesia is limited as much as possible. 5. Apply camouflage techniques instead of laser treatment. 6. The patient has no negative impact

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			<p>both on short as well as long term.</p> <p>5. Being well informed about the expected results both on short and long term. The effect on the face is normally better than on the legs.</p> <p>6. Psychological support.</p> <p>7. Psychosocial support.</p> <p>8. Knowing what to do and not to do before and after treatment (eg. no sun exposure).</p> <p>9. At what age could laser treatment start best?</p> <p>10. Is laser treatment requested by the patient and/or parents (whose need is laser treatment and why)?</p>	<p>5. Knowing what to do before and after treatment.</p>	<p>regarding psychological aspects.</p> <p>7. Timely access to psychological support of patients and family members.</p>

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Surgery	Lifetime	Depending on the locations of the markings.	<ol style="list-style-type: none"> 1. Surgery might be required in case of complications. 2. Psychological support. 	<ol style="list-style-type: none"> 1. Right medical experts performing surgery. 2. Financial support in case costs cannot be reimbursed. 3. Psychological support parent(s), family and friends. 	<ol style="list-style-type: none"> 1. Timely access to the right expertise center and medical specialists. 2. No physical damage. 3. Timely access to psychological support of patients and family members. 4. The patient does not experience negative impact regarding psychological aspects.
Follow up care 	Lifetime	Depending on the locations of the markings.	<ol style="list-style-type: none"> 1. Regular monitoring depending on location of markings eg. annually eye fluid pressure in case markings are located on the forehead and/or around the eyes. 2. Perform MRI scan of the brain. 3. Psychological support. 	<ol style="list-style-type: none"> 1. Right medical experts in multidisciplinary team in charge of follow-up. 2. Financial support in case costs cannot be reimbursed. 3. Psychological support parent(s), family and friends. 	<ol style="list-style-type: none"> 1. Timely access to the right expertise center and medical specialists. 2. Timely access to psychological support of patients and family members.

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Palliative care & death Premature due to complications or by age.	End of life		<ol style="list-style-type: none"> 1. Psychological support. 2. The patient receives the best holistic care. 3. The patient knows and shares his/her last wishes. 4. Smooth transition from care to home, hospice, etc. 	<ol style="list-style-type: none"> 1. Psychological support parent(s), siblings, grandparents, friends. 2. For the final period a hospice could be used. 3. The last wishes of the patient are known. 	<ol style="list-style-type: none"> 1. For the patient the best medical, psychological and pain care is available. 2. Last wishes of the patient are respected. 3. Affordable and timely access to care facility. 4. Timely access to psychological support of patients and family members. 5. Medical and genetic data made available for research.
In memoriam	After death	Not applicable.	Not applicable.	<ol style="list-style-type: none"> 1. Psychological support parent(s), siblings, grandparents and friends. 	<ol style="list-style-type: none"> 1. Timely access to psychological support of patients and family members. 2. Parent(s), siblings, grandparents and friends have accepted the reality and can deal with the loss.

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					3. On social media a memoriam page is available.

Miscellaneous information

1. Central patient health record containing all (medical) data from all involved health care providers. This environment is under control of the patient and/or parent(s).
2. Patient data is collected (anonymously) and used for research and medical diagnosis for other patients as well.
3. Based on big data, collected from other patients, complications can be predicted and prevented.

Disclaimer:

The information above is based on collection of experience for over 20 years as patient organisation and the feedback we collected given by our patients/parents from all over the world. The information has not been checked yet with medical specialists. Despite all care we have taken, we cannot accept responsibility if information appears to be incorrect.

This is the short version. In the comprehensive version details are provided per body region.

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