

MEDICAL CONTACT DETAILS

My Doctor

- Name
- Contact Details

My Fanconi Anaemia Specialists

- Name
- Medical Centre
- Department
- Contact Details

- Name
- Medical Centre
- Department
- Contact Details

Other Healthcare Providers

- Name
- Medical Centre
- Contact details

MY PATIENT SUPPORT GROUP

- Organisation
- Country
- Contact details

General Information

Fanconi Anaemia: a cancer-predisposition condition with many faces.

Fanconi Anaemia (FA) is an inherited disorder leading to congenital physical features in 75% of patients. Most common physical anomalies include skin pigmentation spots, thumb malformations and short stature. Physical appearance varies greatly: from clearly present anomalies to totally absent. At a young age, low blood counts occur frequently: red cells - anaemia, leading to fatigue; low thrombocytes (actually more common), leading to bruises and a bleeding tendency).

The underlying problem is the inability to repair naturally occurring DNA damage. This leads to a highly increased risk of developing malignancies: leukaemia, head and neck cancer and gynaecological tumours are the most common, occurring often and at a young age. Because of the reduced ability to repair DNA damage, there are also significant risks in cancer treatment: doses have to be adjusted drastically and many drugs cannot be used.

Most patients are recognised and diagnosed as children, but not all! Impaired blood production at a relatively young age, uncommon cancers (head and neck, gynaecological in women) at a young age and familial occurrence of cancers at young age or unusual toxicities of cancer treatment can all hint at this cancer predisposition syndrome.

Donor stem cell transplantation is often required for children and adolescents with FA and is curative for this part of the condition. It requires a specialised team. However, the increased risk of head and neck cancer and gynaecological tumours cannot be cured in this way.

We ask you – as a healthcare-provider - to pay attention to the uncommon features of this condition: please watch out for signs of malignancies.

Your patient can help you if you need more information about this challenging condition.

Thank you for your attention.

Prof.Dr. Ruud Brakenhoff, VU Medical Centre, Amsterdam on behalf of the FA Europe Network.

The US Fanconi Anemia Clinical Care Guidelines, Fifth Edition, 2020, is a publication of the Fanconi Anemia Research Fund and is the most recent and comprehensive set of guidelines worldwide.

For help with cancer treatment advice you can ask Fanconi Anaemia experts using the FA Virtual Tumour Board at www.faeurope.org/vtb

Clinical Care Guidelines

FA EUROPE

Connecting Fanconi Anemia Patients and Professionals Across Europe

Fanconi Anaemia Passport

NAME



www.faeurope.org

Fanconi Anaemia Passport

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PERSONAL DETAILS

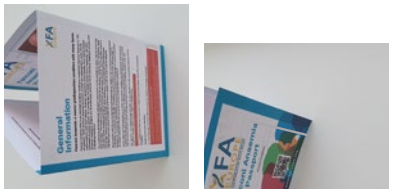
- Name
- Patient ID
- Address
- Phone Number
- Email Address
- Nationality and First Language

FAMILY CONTACT DETAILS

- Relationship e.g. Mother, Father, Carer
- Address
- Phone Number
- Email Address

MY MEDICAL DETAILS

- FA genotype e.g. FA Type A C, G
- Physical signs
- Blood type
- **Bone Marrow Transplant**
  - ☐ Yes ☐ No Date
  - Where
  - Who By



- Recent medical history /current treatment and medication
- List of allergies
- Other Notes for doctors