

## Kinderchirurgie

# Follow Me outpatient clinic for congenital malformations; information for parents (Engelse vertaling)

This flyer provides you with information on your child's appointment at the Follow Me outpatient clinic for congenital malformations.

### What is Follow Me outpatient clinic for congenital malformations?

Your child has been treated in the Emma Children's Hospital of the Amsterdam UMC, for one of the following congenital malformations:

- esophageal atresia
- congenital lung malformations
- gastroschisis
- omphalocele
- Hirschsprung's disease
- anorectal malformation
- Short Bowel Syndrome
- sacrococcygeal teratoma

We find it important to follow up your child's health after discharge from the hospital. This way we can detect any problems on time.

Therefore, we invite you and your child to the Follow Me outpatient clinic for congenital malformations for check-ups at specific ages

At the Follow Me outpatient clinic for congenital malformations, a multidisciplinary team of doctors and other health care professionals such as nurses, physiotherapists and psychologists, will check your child's growth, development and quality of life.

### Preparations for the appointment at the Follow Me outpatient clinic

You will receive an appointment letter for your child's appointment at the Follow Me outpatient clinic for congenital malformations.

Previously to your visit to the Follow Me outpatient clinic, we would like to get an impression of any concerns or issues you might have regarding your child's health. For this reason, we ask you to fill in questionnaires about your child's health and wellbeing. The doctor will discuss the results from the questionnaires with you (and your child) during the appointment at the Follow Me outpatient clinic.

In order to fill in the questionnaires, it is important to register for KLIK ([www.hetklikt.nu](http://www.hetklikt.nu)) for questionnaires regarding the quality of life of your child and your own wellbeing and My Chart (the hospital's digital patient portal) for a questionnaire about the physical health of your child. If your child is aged 0-7 we ask you to fill in the questionnaires. If your child is aged 8 years or

older, we ask both you and your child to fill in the questionnaires. Of course only if your child is capable of doing so.

## **KLIK**

Regarding activation of KLIK: You (and your child) will receive an invitation letter for KLIK with instructions for registration. Most questionnaires in KLIK are available in English.

## **Mijn Dossier**

Regarding activation of My Chart: you can activate My Chart at the Patient Administration of the Amsterdam UMC hospital. The questionnaires in My Chart are only available in Dutch.

## **The appointment at the Follow Me outpatient clinic**

The Follow Me outpatient clinic for congenital diseases is located in the AMC building of Amsterdam UMC. The appointment consist of multiple checkups by various health care professionals. These checkups will take place in one day (as much as possible). Which caregivers are involved with your child's checkups depends on the type of malformations and age of your child. You will find an overview of these caregivers in the appointment letter you will receive.

You are allowed (as a parent/caregiver) to be present during your child's checkups, except for the development tests for children from the age of 6 years. To increase the reliability of the tests, we ask you to take place in the adjoined waiting area.

## **Laboratory & Radiology**

It is possible your child also has to go to the Laboratory for blood and/or urine tests or the department of Radiology for X-ray photographs previous to the appointment. These test can be performed on the same day as your appointment. Whether this is necessary depends on the type of malformation and age of your child. You will be informed about this previous to the appointment.

## **Additional function tests**

It is possible your child will also get an appointment for a pulmonary function test and/or esophagus function test previous to the appointment. These test cannot be performed on the same day, because the doctors need time to analyze the test results. You will get a separate appointment for this. Whether this is necessary depends on the type of malformation and age of your child. You will be informed about this previous to the appointment.

## **After the appointment at the Follow Me outpatient clinic**

After the appointment at the Follow Me outpatient clinic, you will receive a digital report with the results of the appointments in My Chart. If necessary, at the end of the day, one of the members of the team will discuss the results with you over the phone.

## **Scientific research**

As an academic hospital we are always open to learn more about the long-term effects of malformations and the effects of our treatments. To gain more knowledge about long-term effects in patients with congenital malformations and to develop better treatment strategies,

we do scientific research. We would also like to use the data we collect from your child during the hospital admission(s) and appointments at the Follow Me outpatient clinic for the purpose of scientific research. We will ask your permission for doing so during the appointment at the Follow Me outpatient clinic. We will handle your child's data strictly confidential and coded. If you have given us permission for the use of data for scientific research, you always have the right to later withdraw your permission.

## More information?

The following video gives you an impression of the appointment at the Follow Me outpatient clinic for congenital malformations:

You can watch the video by scanning the QR-code with your smartphone.

Or copy the following URL in to your webbrowser:

<http://bit.ly/FollowMeAangeborenAandoeningen> .



For questions you can contact the Follow Me case managers by email:

[followmekinderchirurgie@amc.nl](mailto:followmekinderchirurgie@amc.nl) .

In case you want to reschedule your appointment at the Follow Me outpatient clinic, you can contact the outpatient clinic's appointment-desk by phone or email:

Phone number: 020 - 566 8000

E-mail address: [ekzafspraken@amc.nl](mailto:ekzafspraken@amc.nl)