



THALASSAEMIA
INTERNATIONAL
FEDERATION

TIF European Thalassaemia & Sickle Cell Disease Symposium
13 December 2020 | 10:15

SELF-MONITORING: THALIA MOBILE APP



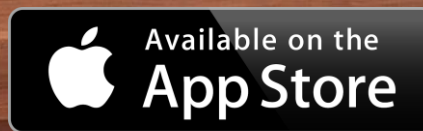
Eleni Antoniou
Senior Policy Officer
Thalassaemia International Federation



THALIA

Mobile App

*The skilled assistant of people with
thalassaemia and sickle cell disease*



A LOOK INTO THE MOBILE APP







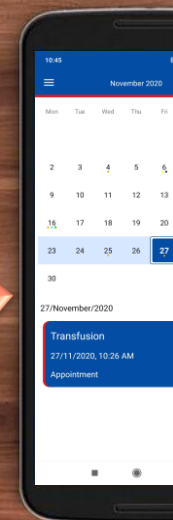
- > Why THALIA?
- > Why an assistant?
- > How it works



1.

WHY THALIA?

A name of empowerment

- 
- 
- 
- 
- 
- ✓ **THALIA** stands for “**THAL**assaemia **In Action**”
 - ✓ An **abbreviation** for the strategic collaboration of TIF with the European Commission
 - ✓ “**In action**” is defined as “the process of doing something in order to make something happen or to deal with a situation” (Oxford Dictionaries)



For the empowerment
of affected people



For a better daily
management of the disease



2.

WHY AN ASSISTANT?

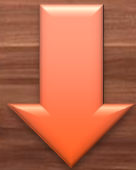
And why a Mobile App?

The problem

Why an assistant?

Patients tend to miss their transfusion **appointments**.

Patients tend to forget to take their **medication**.

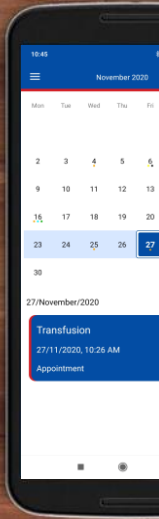


Adherence leads to better clinical outcomes & better quality of life

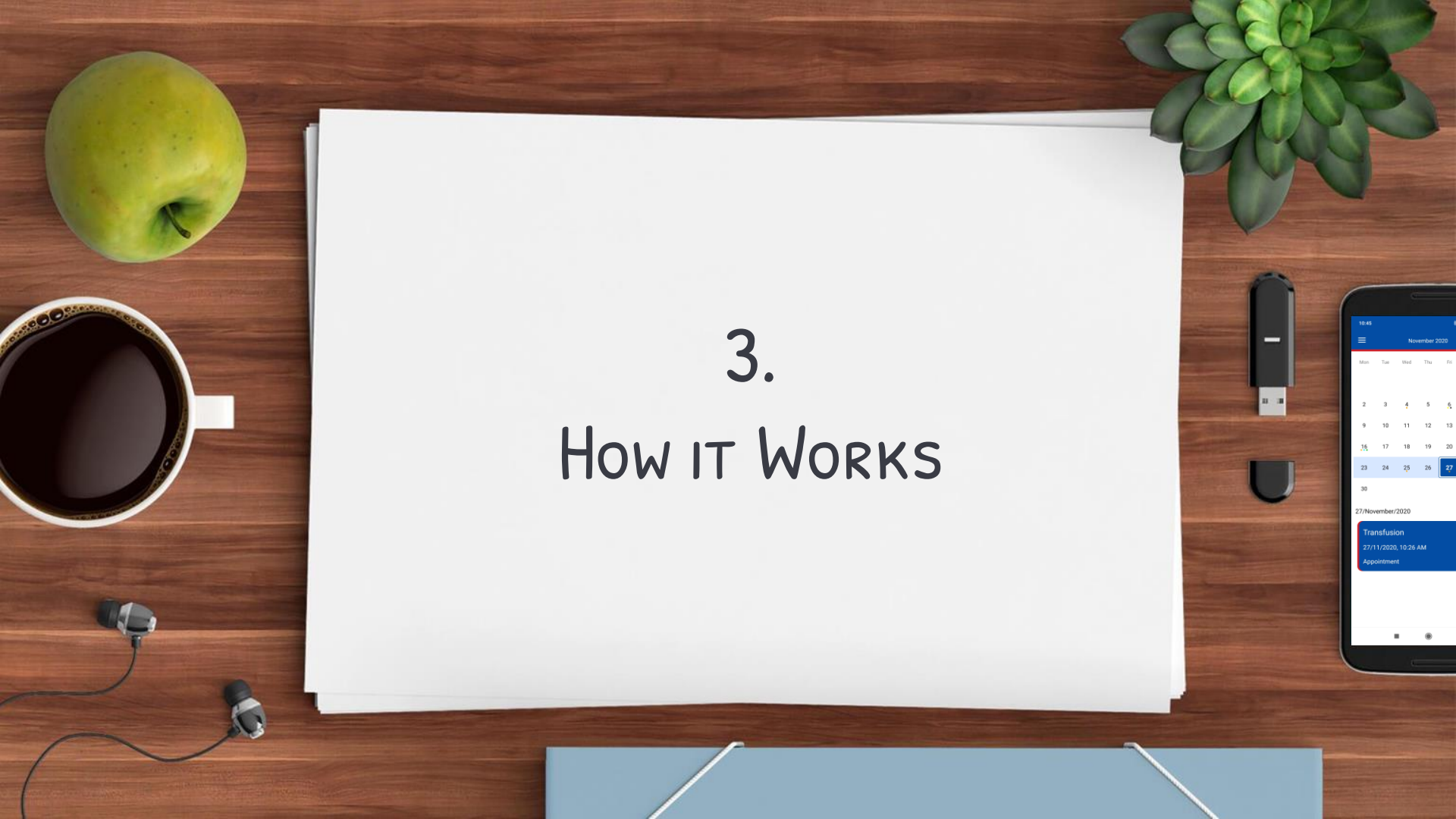
Why not an assistant?

Why a Mobile App?

- ✓ Easy to use
- ✓ Portable (always around)
- ✓ Data safety
- ✓ Can be tailored to the community's needs
- ✓ Can be kept up-to-date



3. How it Works



**FIRST
LAUNCH**



THALIA will ask you to
enter basic
information about
yourself and your
medication.

SUGGESTED PERIOD FOR BLOOD TRANSFUSION

The screenshot displays a mobile application interface with a calendar and a list of indicators. The calendar shows the month of December 2020, with the 2nd day highlighted. The indicators list includes Transfusion, Appointment, Medication, Pain level, Mood level, and Ferritin level. A blue box at the bottom indicates the suggested period for next transfusion.

epic 56% 15:05

December 2020

Mon Tue Wed Thu Fri Sat Sun

1 2 3 4 5 6

Indicators

- Transfusion
- Appointment
- Medication
- Pain level
- Mood level
- Ferritin level

Suggested period for next transfusion

OK

No entries found

epic 56% 15:06

December 2020

Mon Tue Wed Thu Fri Sat Sun

1 2 3 4 5 6

7 8 9 10 11 12 13

14 15 16 17 18 19 20

21 22 23 24 25 26 27

28 29 30 31

02/December/2020

10 g/dL

02/12/2020, 03:06 PM

Transfusion

NEVER MISS A DOSE AGAIN

> Add Medication

epic 18:05 56% 15:05

← Add medication Add

Enter medication name
Deferasirox

Enter dosage
125mg

On which day(s) do you need to take the medication?

<input checked="" type="checkbox"/> Monday	<input checked="" type="checkbox"/> Tuesday
<input type="checkbox"/> Wednesday	<input type="checkbox"/> Thursday
<input checked="" type="checkbox"/> Friday	<input checked="" type="checkbox"/> Saturday
<input type="checkbox"/> Sunday	

How frequently do you take the medication daily?

Twice daily ▾

15:00	1st dose
20:00	2nd dose

Medication Alerts

18:10
Wednesday, 2 December

Wi-Fi Mobile data Bluetooth Vibration Auto-rotate

Thalia • Now
Medication reminder
Deferasirox, 125mg

DONE SNOOZE FOR 10 MINUT...

Xd STICK 2000mg Adobe Xd Click & Win Your Phone Jira Adobe Scan

Appa Travel my epic Games Crypto

Play Store Photos Gmail Calendar Google

Phone Messages App Store Chrome

epic 18:20 86%

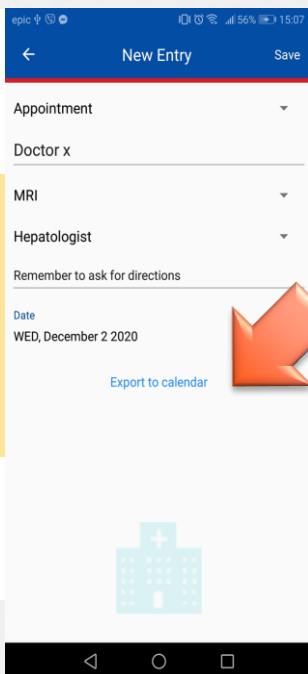
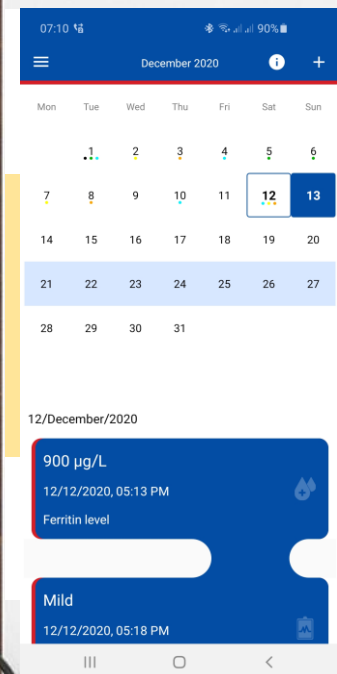
Medication reminder

Deferasirox, 125mg

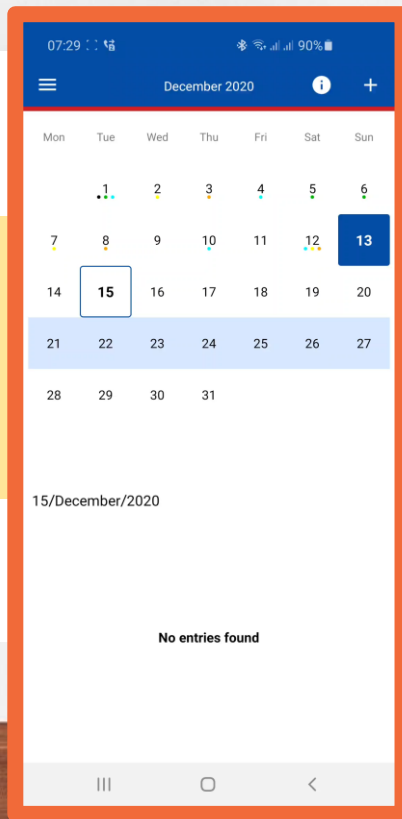
Done Snooze (10 minutes)

⌚

NEVER MISS AN APPOINTMENT AGAIN



[• REC]



TRACK DOWN YOUR PROGRESS

Different Entry Types

Pre-transfusion Hb Level

Mood Level

Linked to trusted self-monitoring tools

TRACK DOWN YOUR PROGRESS

epic 56% 15:08

New Entry Save

Pain level

Date
WED, December 2 2020 15:08

Select your pain level

0 1 2 3 4 5 6 7 8 9 10

Pain is often associated with prolonged standing, walking, lifting heavy objects and low haemoglobin levels. Get some rest, consider having a transfusion and consult your doctor. Please fill in [this](#) form before your appointment.

Pain Level

And a piece of advice

Brief Pain Inventory (Short Form)

Study ID Hospital #
Do not write above this line

Date: _____
Time: _____
Name: _____
Last First Middle Initial

1) Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?
☐ Yes ☐ No

2) On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.

Right Left Left Right

3) Please rate your pain by circling the one number that best describes your pain at its **WORST** in the past 24 hours.
No Pain 0 1 2 3 4 5 6 7 8 9 10 Pain as bad as you can imagine

4) Please rate your pain by circling the one number that best describes your pain at its **LEAST** in the past 24 hours.
No Pain 0 1 2 3 4 5 6 7 8 9 10 Pain as bad as you can imagine

5) Please rate your pain by circling the one number that best describes your pain on the **AVERAGE**.
No Pain 0 1 2 3 4 5 6 7 8 9 10 Pain as bad as you can imagine

6) Please rate your pain by circling the one number that best describes your pain as it is **RIGHT NOW**.
No Pain 0 1 2 3 4 5 6 7 8 9 10 Pain as bad as you can imagine

7) What treatments or medications are you receiving for your pain?
8) In the past 24 hours, how much **RELIEF** have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.
No relief 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100% Completely relieved

9) Circle the one number that describes how, during the past 24 hours, **PAIN HAS INTERFERED** with you.

A. General Activity
0 Does not interfere 1 2 3 4 5 6 7 8 9 10 Completely interferes

B. Mood
0 Does not interfere 1 2 3 4 5 6 7 8 9 10 Completely interferes

C. Walking Ability
0 Does not interfere 1 2 3 4 5 6 7 8 9 10 Completely interferes

D. Normal work (includes both work outside the home and housework)
0 Does not interfere 1 2 3 4 5 6 7 8 9 10 Completely interferes

E. Relation with other people
0 Does not interfere 1 2 3 4 5 6 7 8 9 10 Completely interferes

F. Sleep
0 Does not interfere 1 2 3 4 5 6 7 8 9 10 Completely interferes

G. Enjoyment of life
0 Does not interfere 1 2 3 4 5 6 7 8 9 10 Completely interferes

Save Print

epic 56% 15:09

New Entry Save

Ferritin level

Date
WED, December 2 2020 15:08

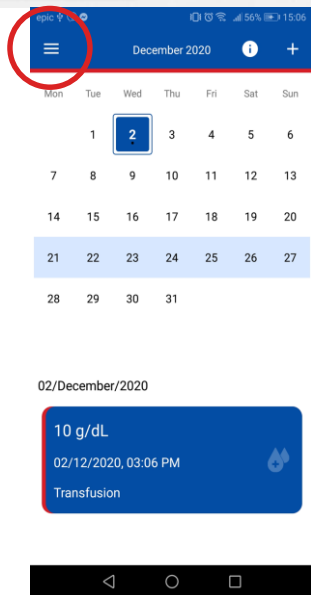
Select your ferritin levels
70 µg/L

Ferritin Level

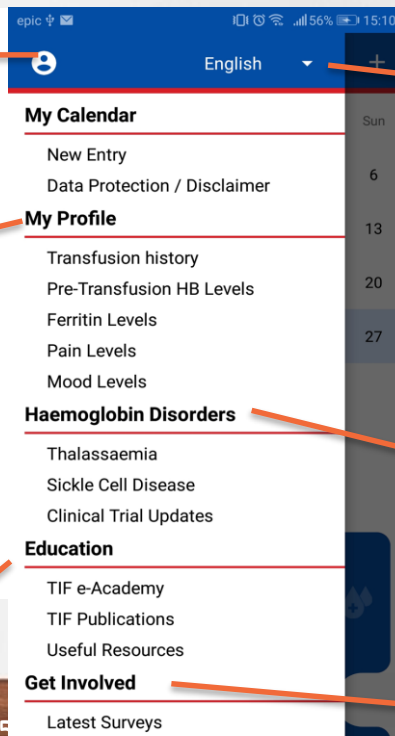
En editable resource to complete before contacting your doctor

A WEALTH OF INFORMATION

Side Menu



User Profile



Language Selection



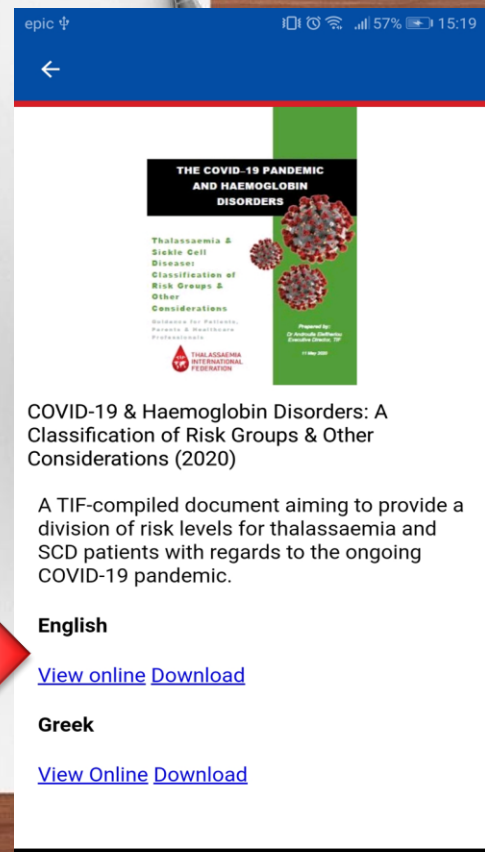
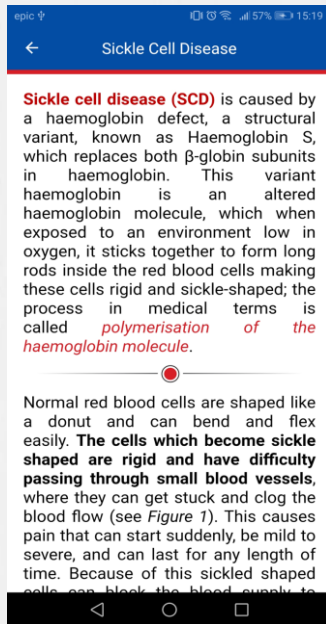
Reporting

Information Pages

Website Pages

Work with TIF

A WEALTH OF INFORMATION



COVID-19 & Haemoglobin Disorders: A Classification of Risk Groups & Other Considerations (2020)

A TIF-compiled document aiming to provide a division of risk levels for thalassaemia and SCD patients with regards to the ongoing COVID-19 pandemic.

English

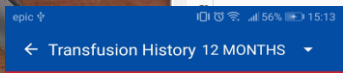
[View online Download](#)

Greek

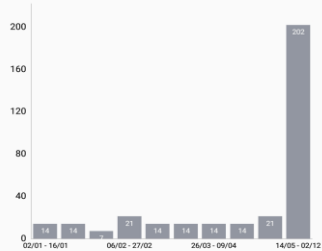
[View Online Download](#)

REPORTING

All graphs are
SHAREABLE



Days between transfusions



Transfusions

Transfusion - 02/01/2020

Transfusion - 16/01/2020

Transfusion - 30/01/2020

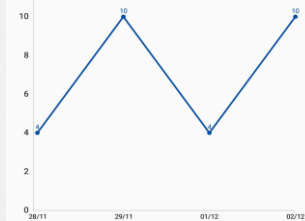
Transfusion - 06/02/2020

Transfusion - 27/02/2020



10 -> Very happy
6 -> Okay
2 -> Bad

8 -> Happy
4 -> Not good
0 -> Very bad



Logs

4 28/11/2020

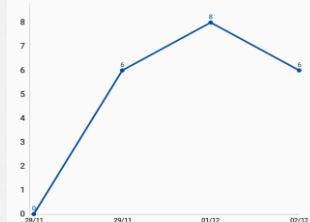
10 29/11/2020

4 01/12/2020



4 -> Moderate
8 -> Severe

6 -> Strong
10 -> Very severe



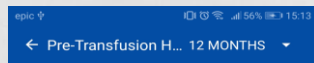
Logs

0 28/11/2020

6 29/11/2020

8 01/12/2020

6 02/12/2020



Logs

10 g/dL 02/01/2020

12 g/dL 16/01/2020

6 g/dL 30/01/2020

7 g/dL 06/02/2020

11 g/dL 27/02/2020

4 g/dL 12/03/2020



THE APP AT A GLANCE

- ✓ A **calendar** tailored to the needs of people with haemoglobin disorders
- ✓ **Reminders** for medications and appointments
- ✓ **Shareable progress graphs**
- ✓ A wealth of **disease-specific information**
- ✓ Available in **English, French and German**
- ✓ **No login** required
- ✓ **No data shared**



IMPORTANT NOTES

- ✓ **Your data is safe.** The information you provide is anonymous, not shared with anyone and **saved on your device.**
- ✓ The THALIA App has been created to assist patients in the management of their disease and is **not a qualified medical opinion.**
- ✓ If you noticed a problem or have a suggestion, **drop us a line** at ***thalassaemia@cytanet.com.cy***. We'd love to hear from you!

The App will be
online TOMORROW!



THANKS!
Any questions?

Find me at thalassaemia-ea@thalassaemia.org.cy