



**Een sterk internet  
voor iedereen**

**SIDN**fonds



**30 NOVEMBER 2017**

# **VAN INNOVATIEF PROJECT TOT SUCCESSTORY MET IMPACT**

**Valerie Frissen  
Directeur SIDN fonds**



Een sterk internet voor iedereen

## **ONZE DOELSTELLINGEN**

- **Versterking van het internet**
- **Empowerment van de gebruiker**
- **Tech for good**



# Grensverleggende projecten op het snijvlak van technologie en samenleving.




Ondersteunde projecten

Zoek op: Thema Type Jaar Wis filter

x 2017



#CROWD OWNERSHIP, BLOCKCHAIN  
**Be a social landlord**



#INTERNET OF THINGS, BLOCKCHAIN  
**The Things Network 2.0**



#EERLIJKE HANDEL IN VOEDSEL, BLOCKCHAIN  
**Blockchain for Food**



#EERLIJK ROYALTY SYSTEEM, BLOCKCHAIN  
**IBT Music**



#CRYPTOCURRENCY (R)EVOLUTIE, BLOCKCHAIN  
**Internet of Coins 2**



#AI, BIG DATA  
**AI for Good**



#VASTGOED VOOR IEDEREEN, BLOCKCHAIN  
**Bloqhouse**



#EMPOWERMENT, TAAL EN REKENEN MET SCRATCH  
**Integratie programmeeronderwijs in taal en rekenen**



#IOT, LORAWAN VOOR IEDEREEN  
**LoRa Server, open source LoRaWAN network-server voor IoT**



## **LAAT JE INSPIREREN**

- **OTLY! – Lior Bornshtain**  
De eerste bankervaring voor kinderen
- **Totem Open Health – Wouter Heijnen**  
Open source alternatief voor ‘wearable health devices’
- **Patiëntenforum Miner – Gerard van Oortmerssen**  
Innovatieve datamining m.b.t. waardevolle informatie uit patiëntenfora

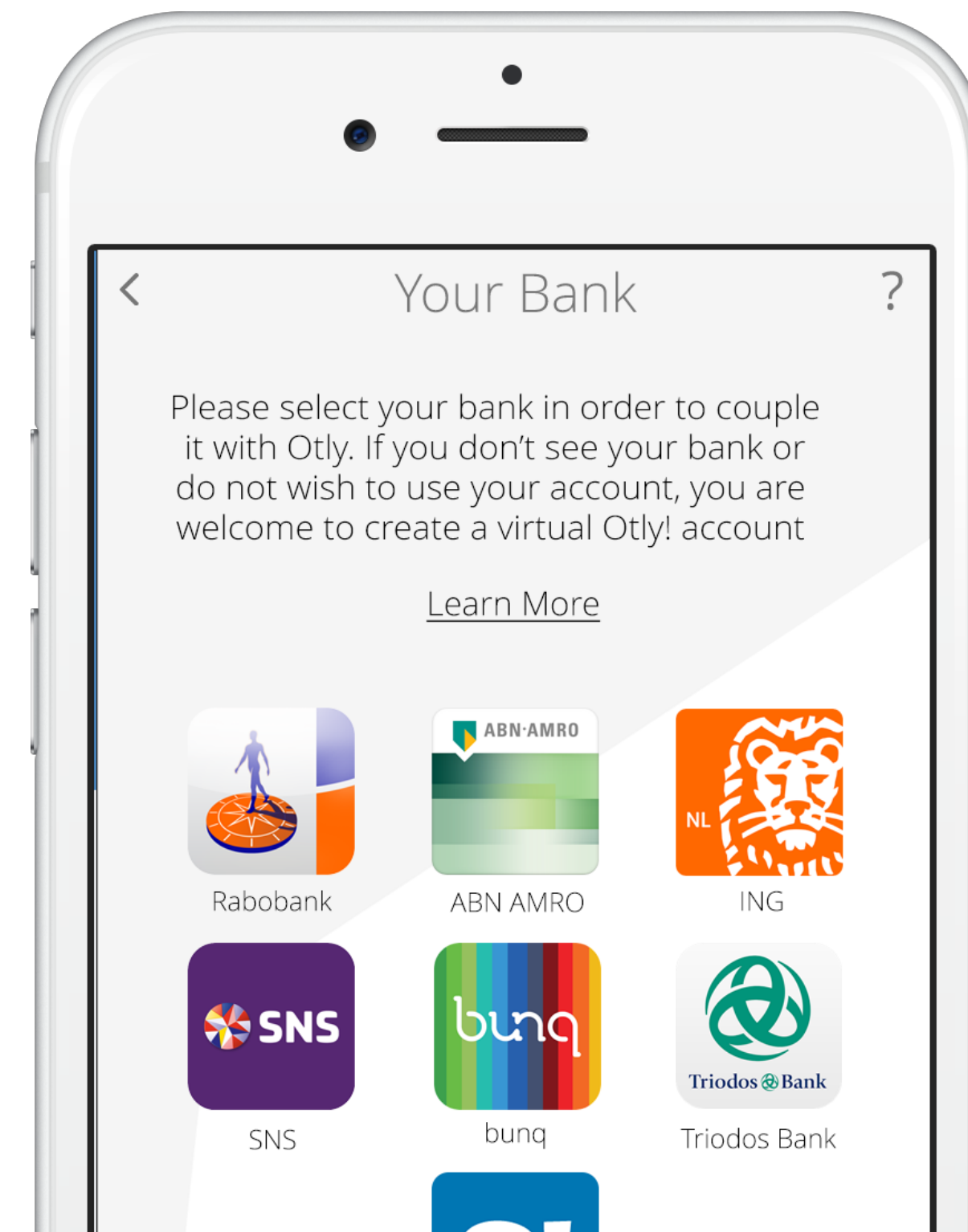
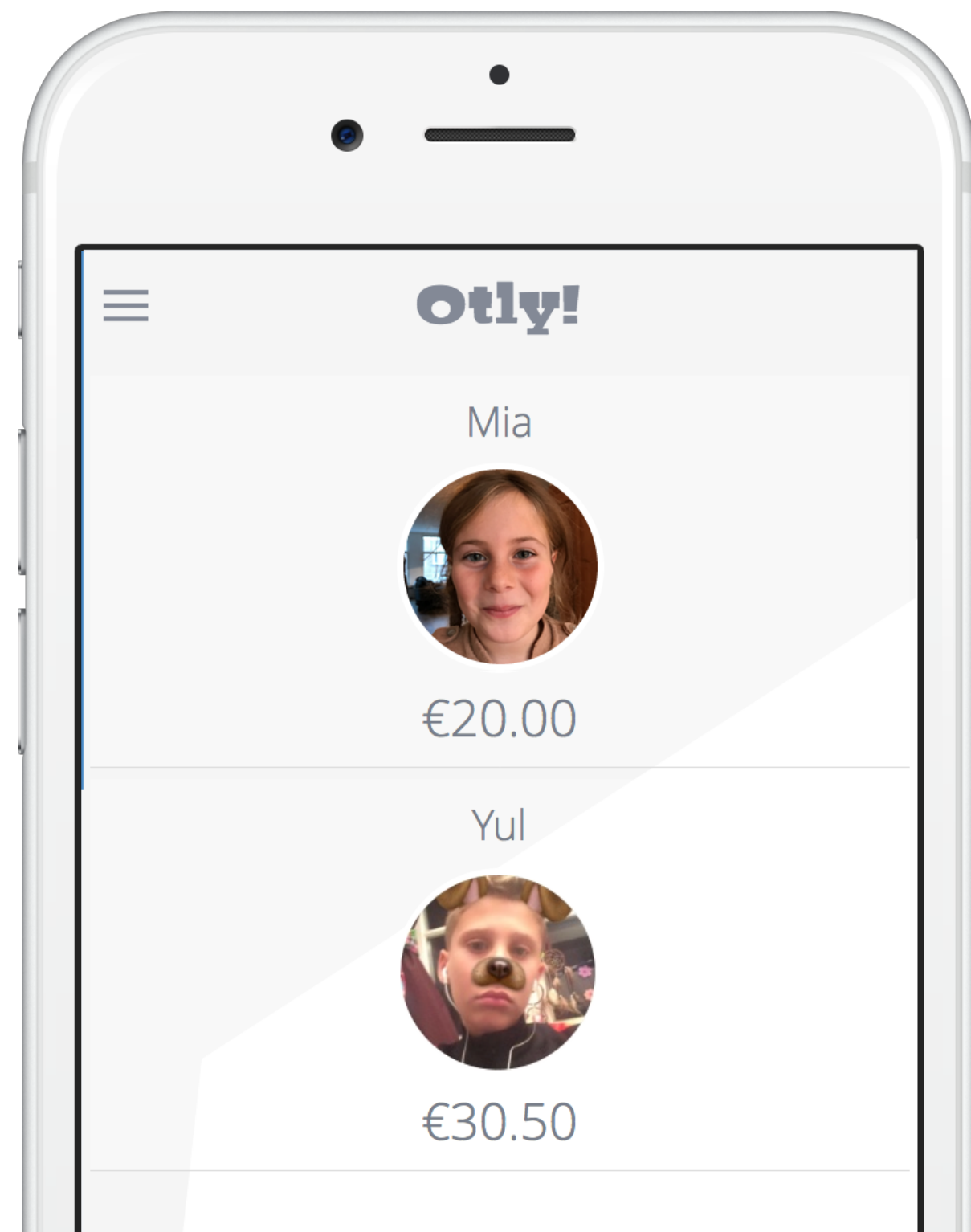
10

**INNOVATIEF  
INTERNETPROJECT?**

**TWEE CALLS PER JAAR  
[WWW.SIDNFONDS.NL](http://WWW.SIDNFONDS.NL)**



The missing layer for kid-friendly banking



It's a cashless society  
and our kids left behind





Allowance is important for financial literacy, but ...



Allowance = Headache



Hard to give and keep track



Hard to spend online



No stimulation to save



But, we are on a mission ...

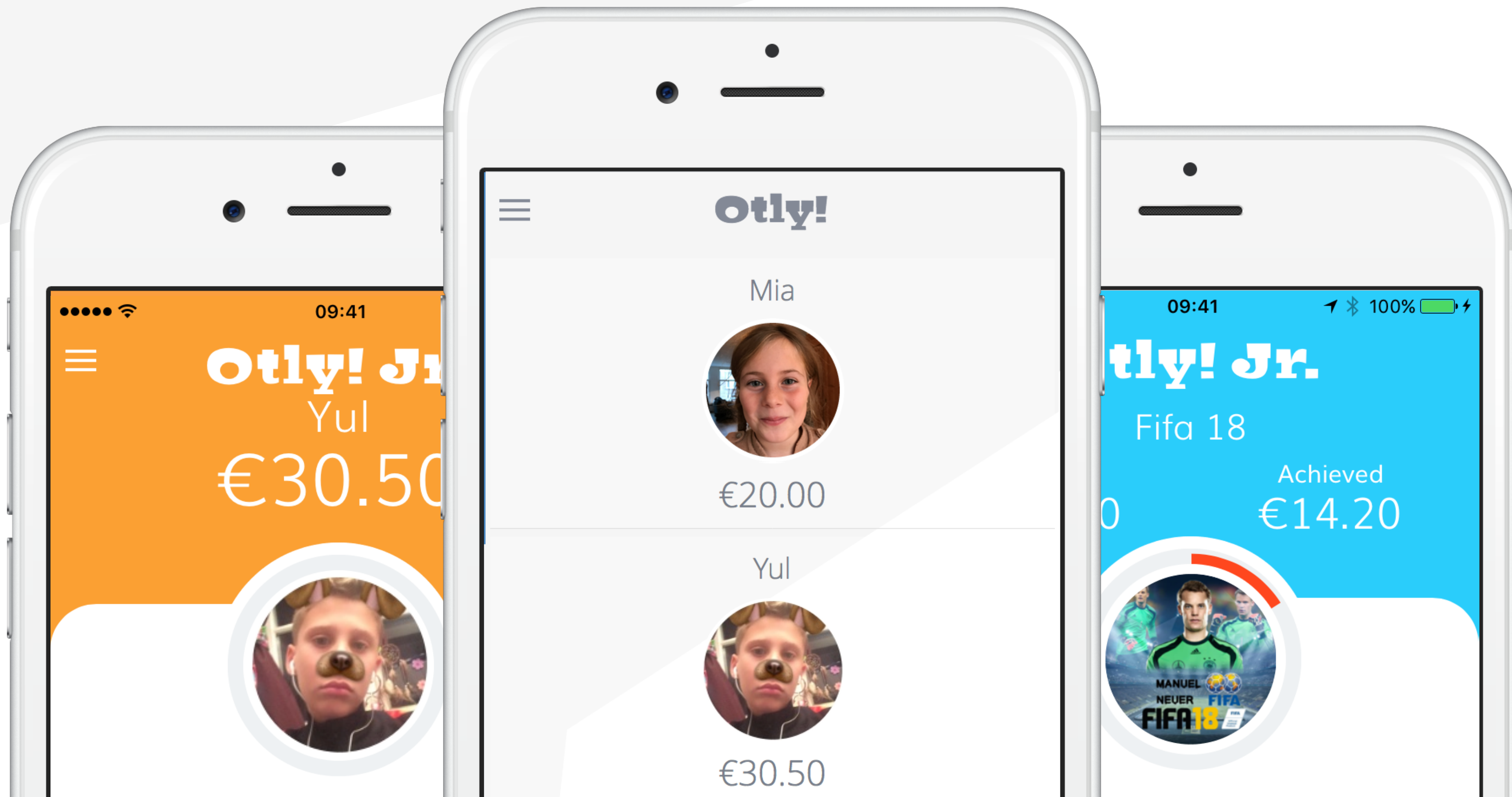




Provide the missing layer  
for kid-friendly banking



# JuniorBanking



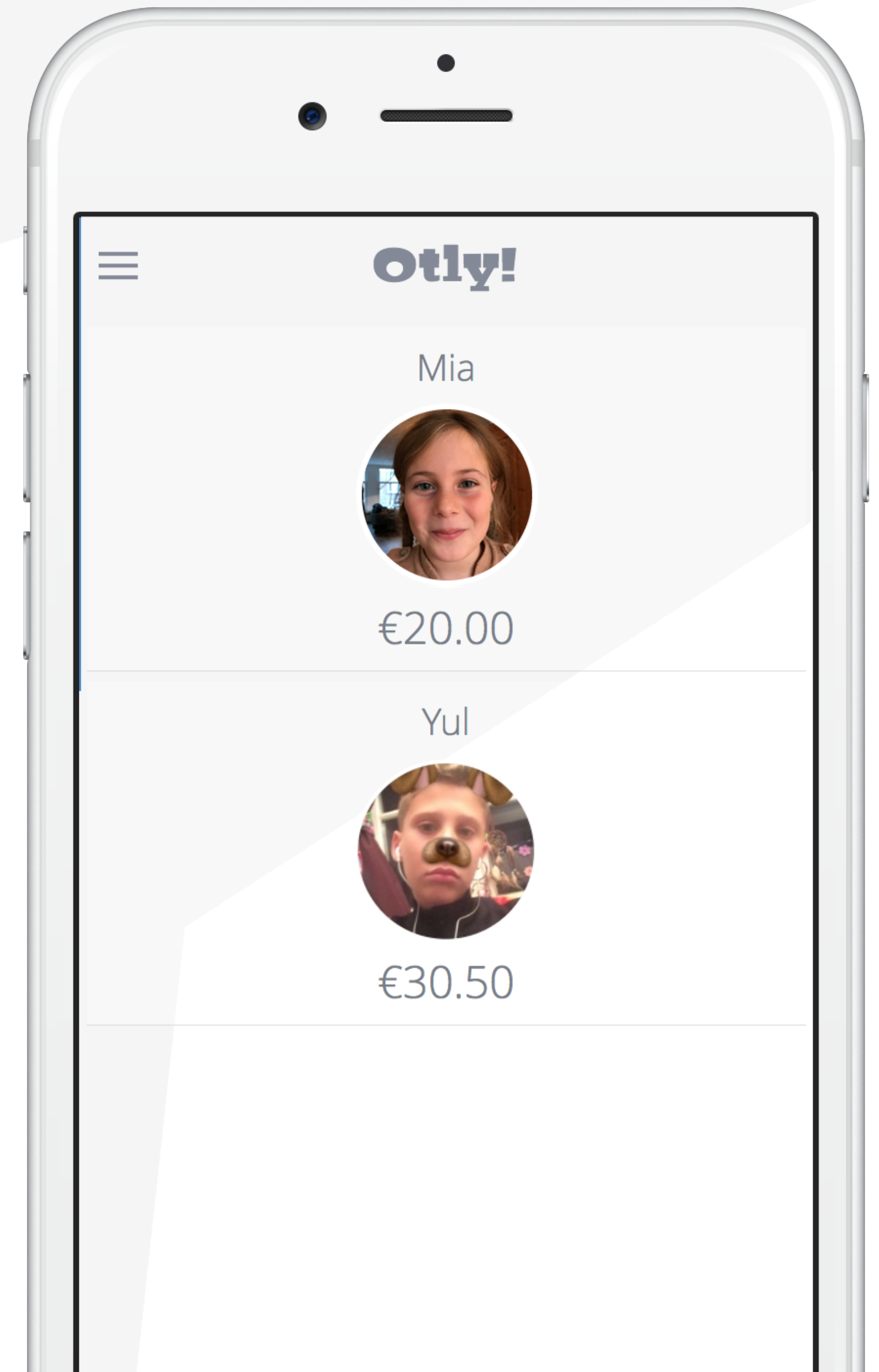


# Junior Banking

Automatic allowance

Saving jars and goals

Holistic overview

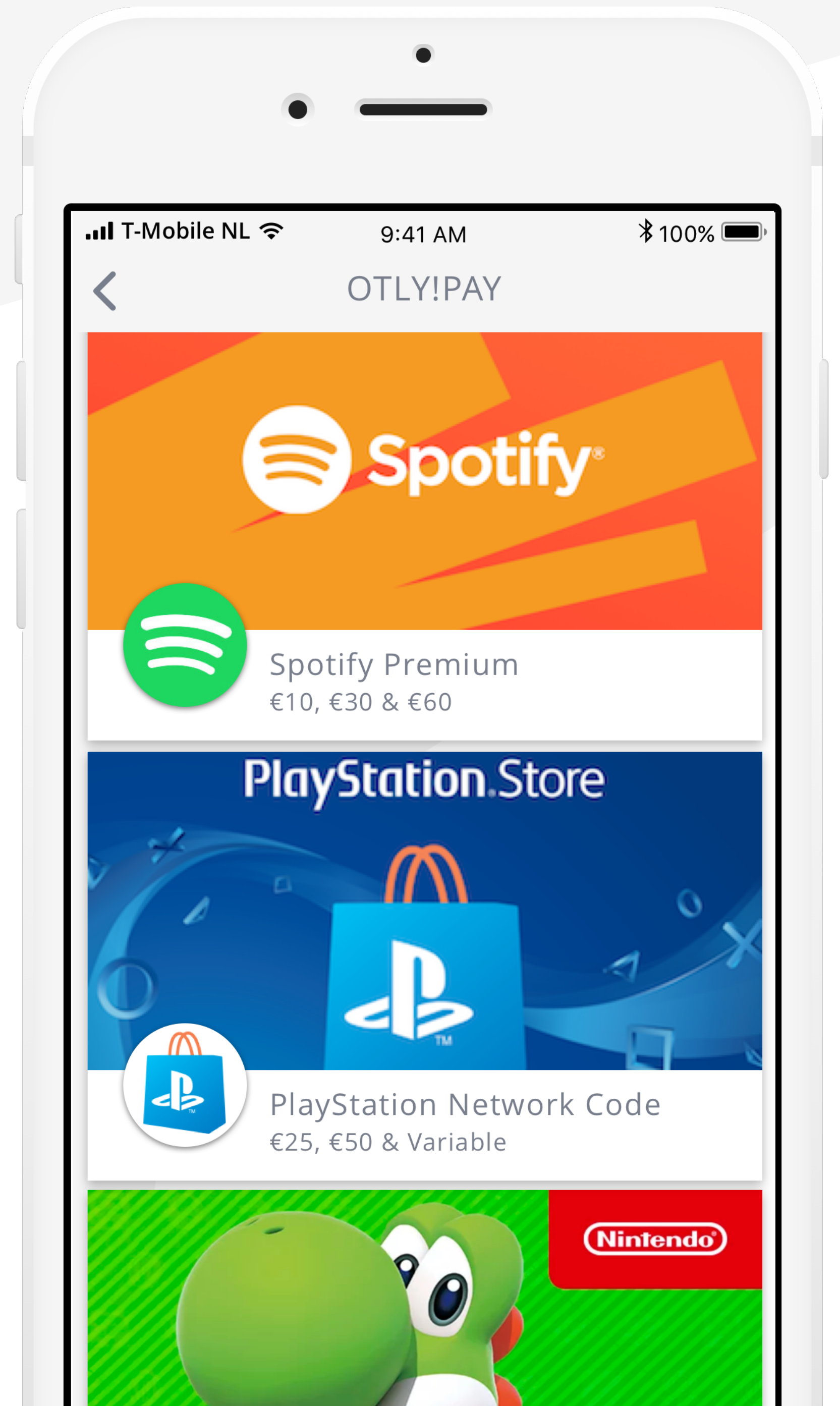


But we decided to take it to the next level...

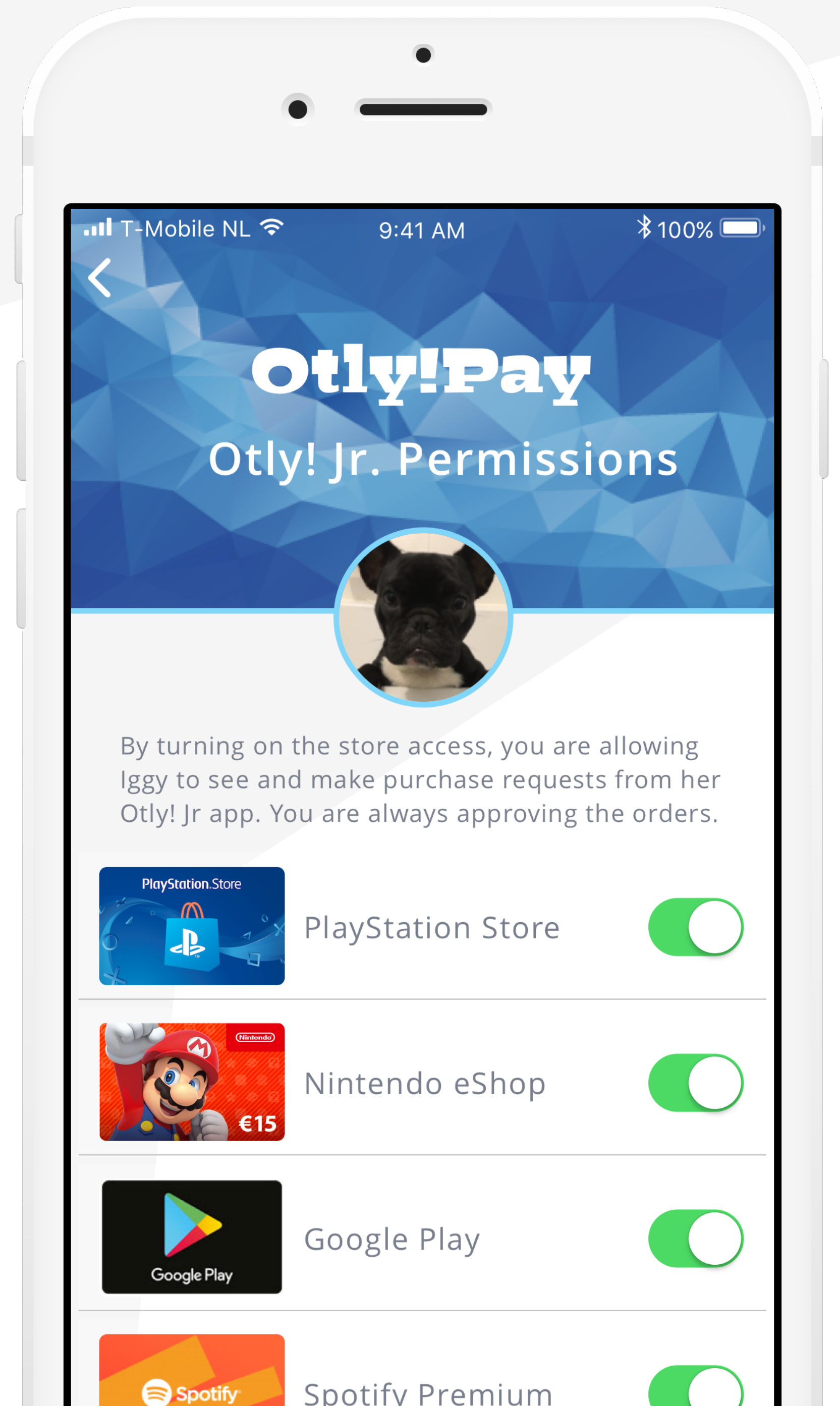


# Otly!Pay

Spend in a safe way

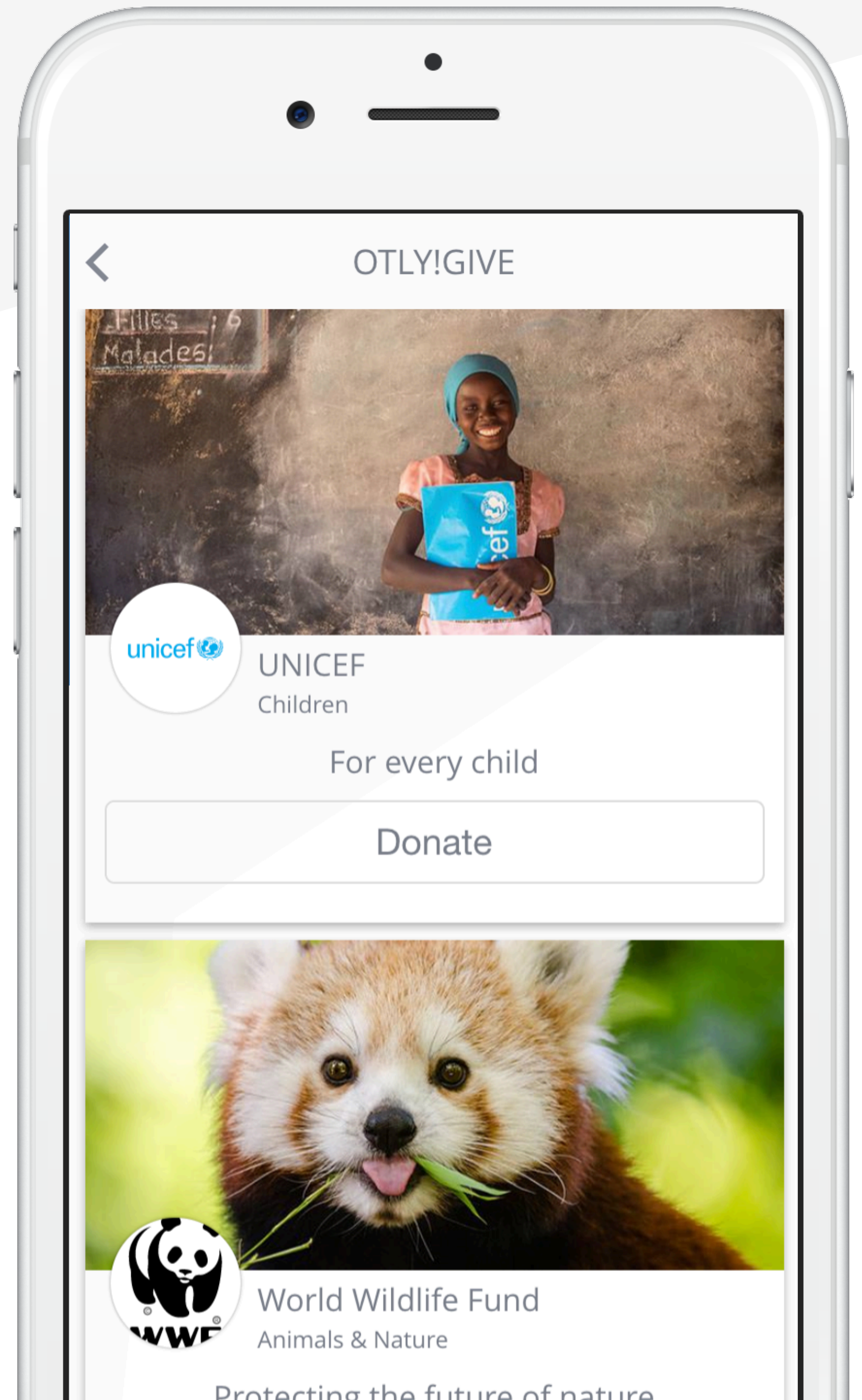


With the parental supervision



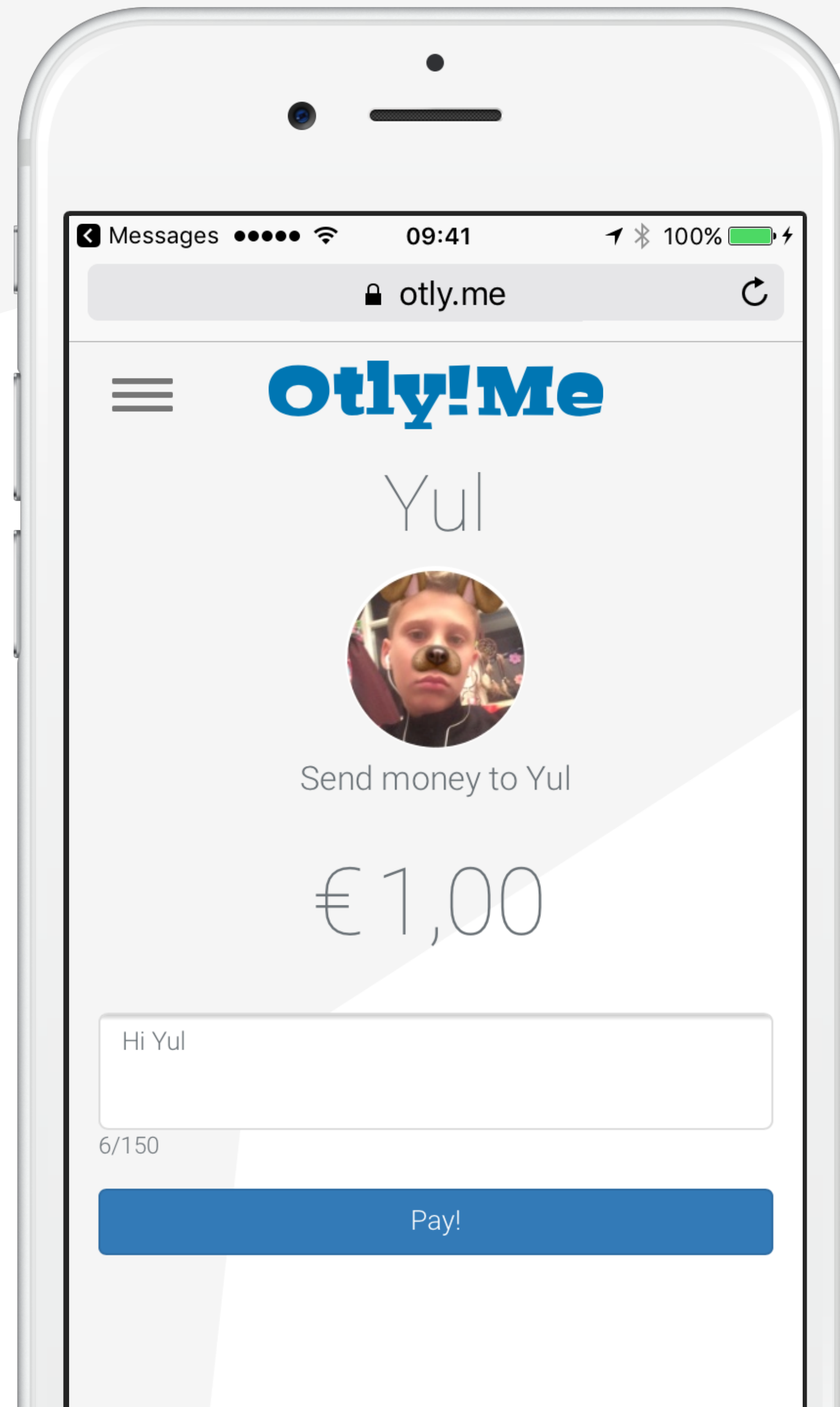
# otly!Give

To care and give

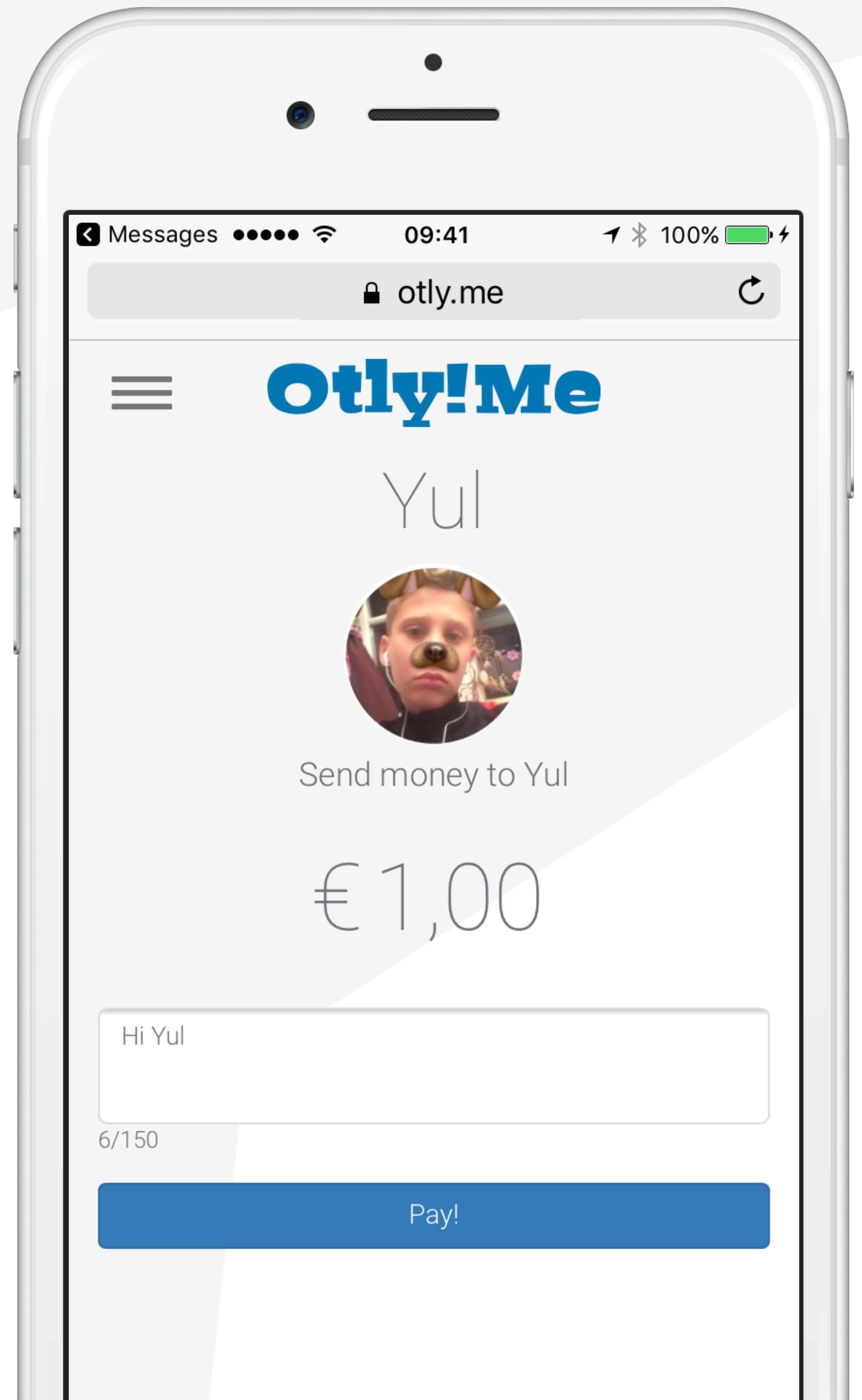


# Otly!Me

Bank with family and friends



<https://otly.me/yul>



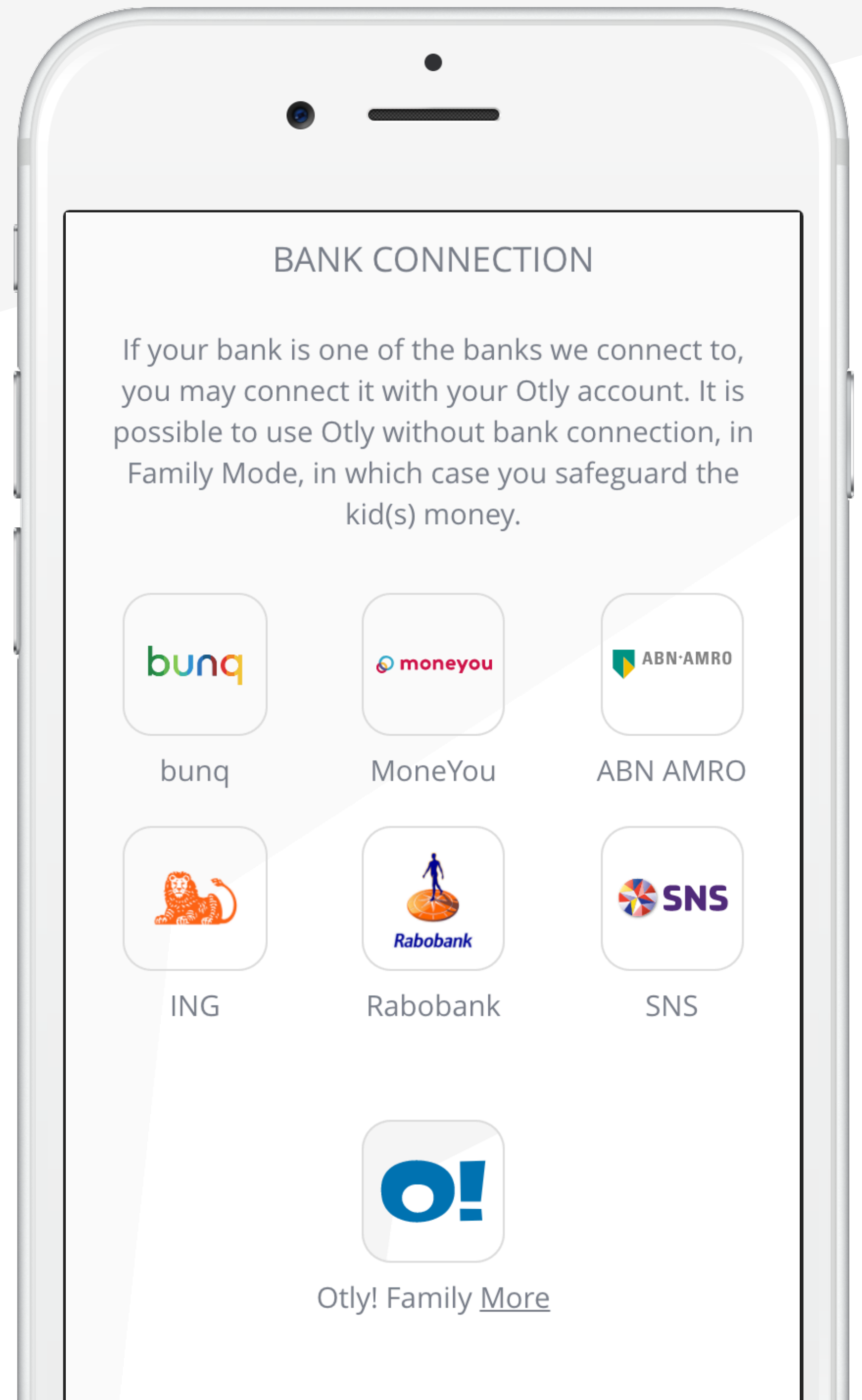
# Otly!Feed

Learn about financial concepts





Otly platform is global and comes in two flavours...



# Bank Base

Connect your bank account



# Family Base

Parents keep the money





Free. Forever and ever...



# Business Model

## Bank affiliation fees

For each connected bank

## Otly!Pay

Commission from merchants (Apple, Google, Sony, etc...)

# Recognition





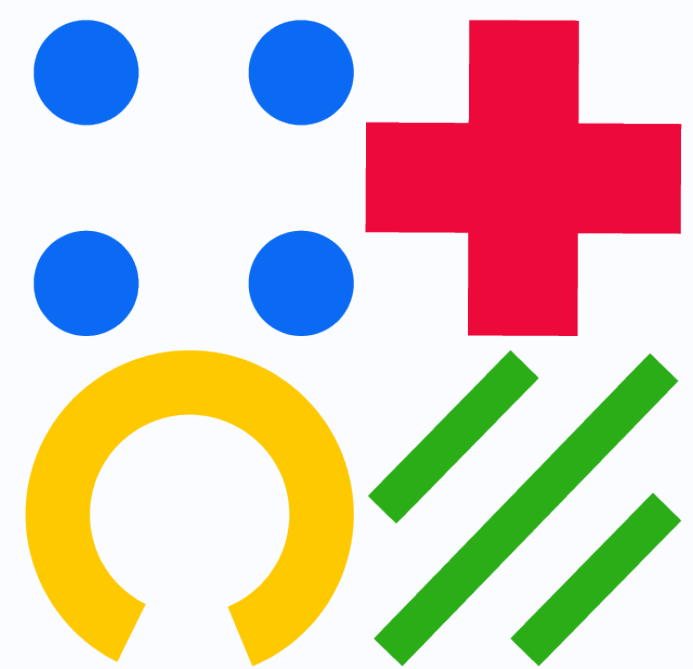


Thank you!





# Innoveren in de zorg met wearable technologie



# Totem







TOP TUBE

228125

The logo consists of a red cross, a yellow circle, and three green diagonal lines, all positioned to the left of the text.

# Totem Open Health

Concept ontwikkelaar voor vraagstukken in de zorg voor en met patiënten, gebruikers, artsen.



# Totem en SIDN

Bijdragen SIDN Fonds: mogelijk gemaakt dat de technologie is ontwikkeld én dat Totem ingezet wordt in de praktijk. En voor de toekomst een waardevolle partner en een waardevol netwerk.



# Impact?

Er zijn toch al heel veel wearables?

Er zijn toch al heel veel applicaties voor de zorg?

Er zijn toch al heel veel goede product ontwikkelaars?



# Impact!

*“Ontwikkelingen in de Geneeskunde gaan soms snel en zijn soms heel geavanceerd. Echter, voor alle diagnostiek geldt dat het van toegevoegde waarde moet zijn en niet te vergeten kosten-effectief. Het ECG is een bewezen effectieve diagnostische methode. Met de ECG van Totem wordt het eenvoudiger en goedkoper. Al met al een fantastisch instrument voor de patiënt, de arts en de onderzoeker.”*

Iwan van der Horst, cardioloog @ UMCG





# Impact!

*“Omdat Totem technologie open source is, is het mogelijk relatief gemakkelijk en tegen lage kosten hun kennis en de onze tot een prototype te brengen en daarna te verbeteren. Dat maakt innoveren leuker en minder ingewikkeld.”*

Jorrit Ebben, Innovation Manager @ Siza



# Impact!

*“Bij de helft van de gevallen van arbeidsongeschiktheid is langdurige stress of burn-out de oorzaak. Door te investeren in technologische ontwikkelingen verwachten we uiteindelijk mensen arbeidsgeschikt te houden. Dat is waar Movir naar streeft. De technologie en visie van Totem helpt ons in deze zoektocht waar dé oplossing niet voor het oprapen ligt”*

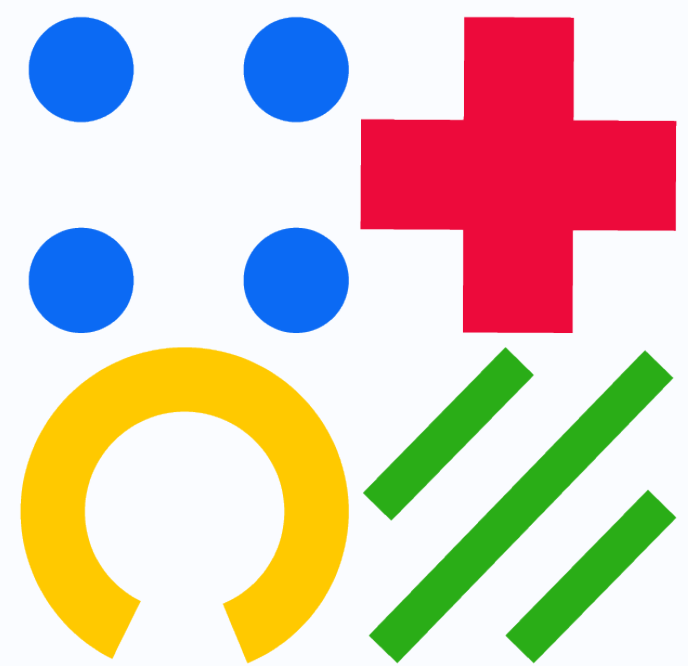
Louis van Drunen, directeur @ Movir



# Impact voorbeeld

Neem kennis van het leven van iemand met de ziekte van Duchenne.

Wouter Heijnen  
[wouter@totemopenhealth.com](mailto:wouter@totemopenhealth.com)  
+31(0)6 1425 7997  
[www.totemopenhealth.com](http://www.totemopenhealth.com)



# Totem



Patientenplatform  
Sarcomen

# Patiëntenforum Miner

**SIDN Connect 2017**

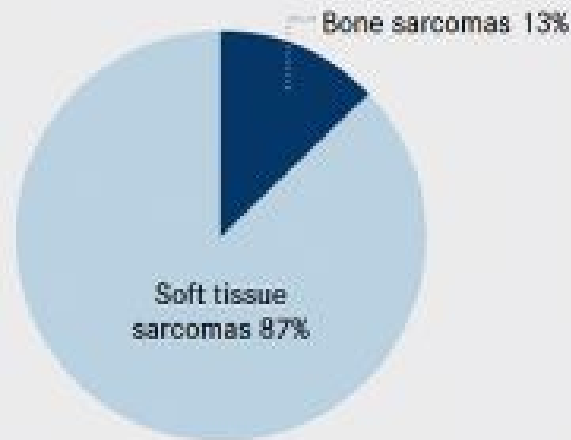
**Gerard van Oortmerssen**

**Patientenplatform Sarcomen  
Leiden University**

# Sarcoom: een zeldzame kanker

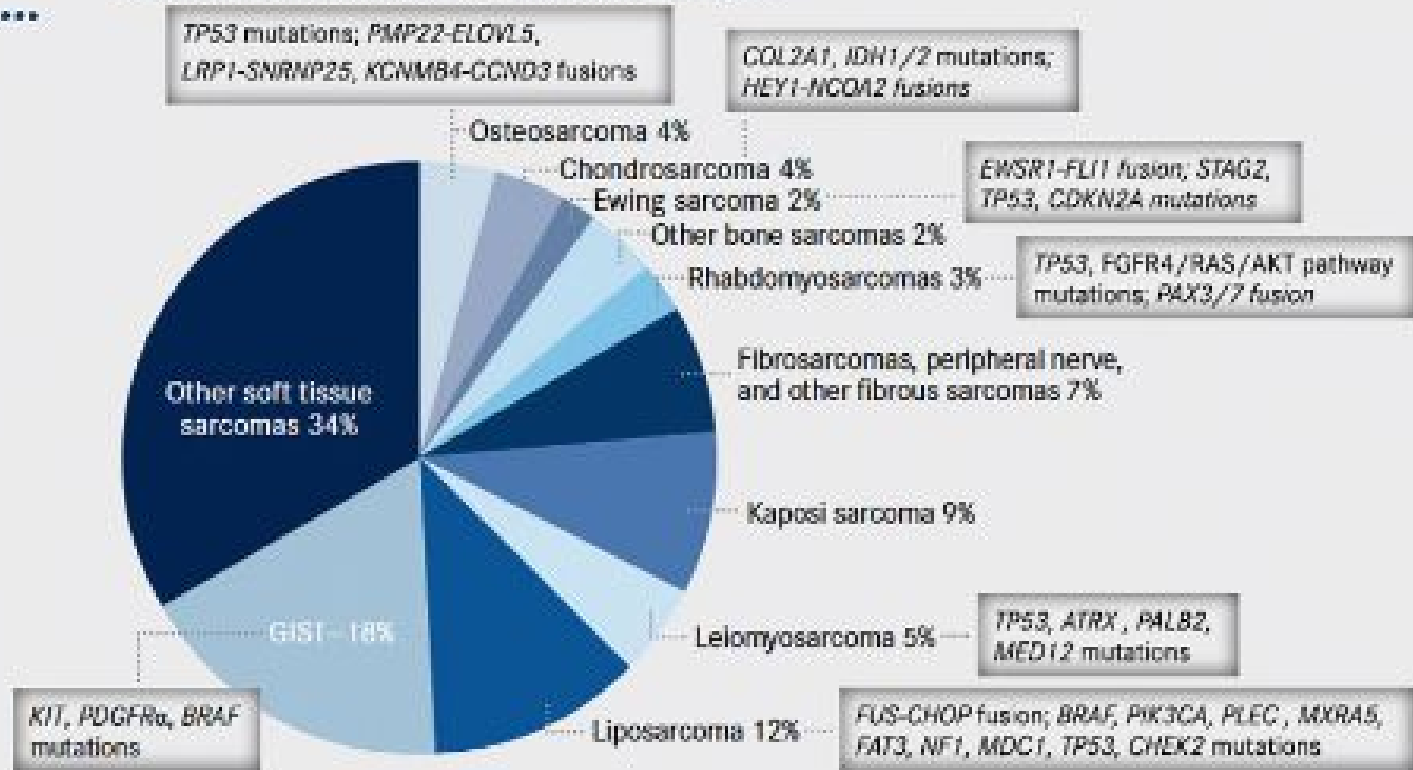
## A Sarcoma Snapshot

### Main Categories




The incidence of sarcoma subtypes is difficult to characterize because of the broad diversity of subtypes and changing classifications, particularly for gastrointestinal stromal tumors (GISTs). This snapshot is based on several epidemiological sources.

### Genomic Abnormalities in Sarcoma Subtypes



# Uitdaging:

- Incidentie laag, weinig patiënten
- Nationale kankerregistratie geeft beperkte info
- Internationale databases nodig maar nationaal is al een probleem
- Krampachtige houding t.a.v. privacy
- Patiënten hebben grote behoefte aan info en contact met andere patiënten



**GIST Support International**  
Public Group

Joined ▾ Share Notifications ⋮

Discussion Members Events Photos Files

Search this group 🔍

Write Post Add Photo / Video Create Poll More

 Write something...

ADD MEMBERS ⓘ

+ Enter name or email address...

MEMBERS 2,431 Members (16 new)



RECENT ACTIVITY

 **Tara Berlingieri Garcia**  
19 hrs · Williston Highlands, FL, United States


Well gister peeps ct scan show no new growth everything else the same lab work good. Keeping me on 800 gleevec. Dr is scheduling a petscan to look deeper into the tumors. So i am thankful and blessed but i wont lie i am a little disappointed


Like Comment Share


Invite by Email

DESCRIPTION  
GIST Support International (GSI) is an all-volunteer organizatio... See More

TAGS  
Cancer · Sarcoma · Gastrointestinal stromal tumor

 Jetty Hamersma-Nicolai, Marina Symcox and 19 others

 **Elaine Cummings** Why?  
Like · Reply · 19 hrs

 **Tara Berlingieri Garcia** Are u asking why i am disappointed. Well i guesa i had been feeling pretty darn good for the most of the past 2 mos i thought for sure the results would show more shrinkage. You know we all hope for a miracle.  
Like · Reply · 1 · 19 hrs


 **Elaine Cummings** Yes I have been trying too, but it just stopped at 18 cm and they will not operate yet. But you do not give up because I do believe God heals. ❤️  
Like · Reply · 4 · 18 hrs

View more replies

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RECENT GROUP PHOTOS [See All](#)



SUGGESTED GROUPS [See All](#)



# Discussie fora: veel en gedetailleerde informatie

## Patients share detailed medical information:

caregiver for mother dx with GIST 12/31/12

31x19x9 cm primary tumor removed 12/12/12

400 mg gleevec 1/15/13 to 12/6/13

Recurrence and removal of 3 masses from the omentum (3.5 to 4.4 cm) on 12/6/13

Sutent 25 mg. since 1/15/14 37.5 mg. since 8/14 (failed Sutent 6/15)

Sorefinib (naxavar) 7/3/15

more tumors removed 7/13/15

Votrient 9/4/15 to 12/30/15

50 tumors removed 1/16/16'

Wildtype Gist NO Kit or PDFRA mutation, SDH intact

# Discussie fora:

- Ontwikkeling van de ziekte
- Behandeling en resultaat ervan
- Bijwerkingen van de behandeling
- Strategieën om met bijwerkingen om te gaan
- Therapie trouw
- Co-morbiditeiten
- Kwaliteit van leven
- Emotionele ondersteuning
- Zoeken naar informatie kost veel tijd!

# PFM: Potential 2016

**SIDN**fonds

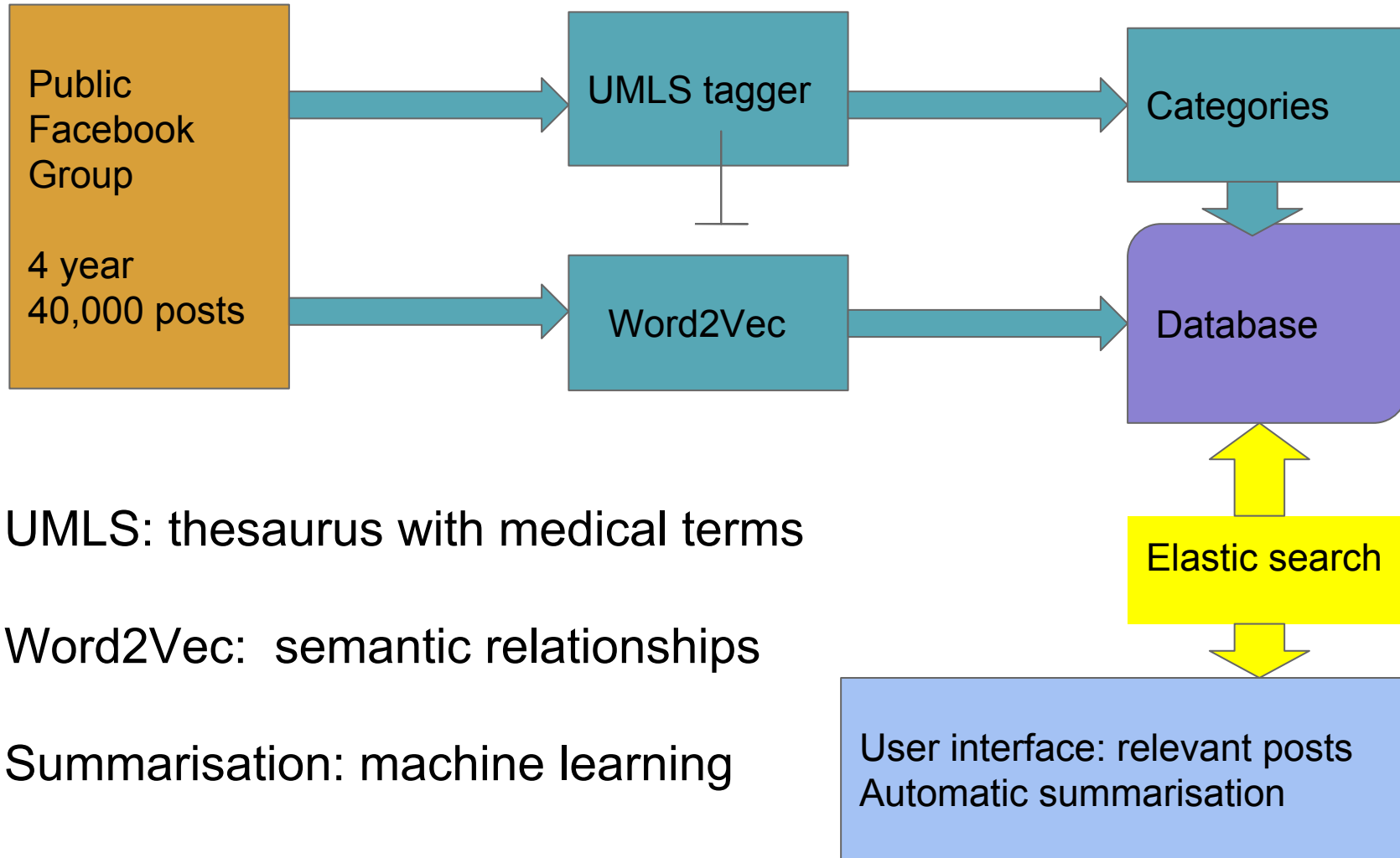


**Radboud Universiteit**



 borstkankervereniging nederland

# Analyse methode



UMLS: thesaurus with medical terms

Word2Vec: semantic relationships

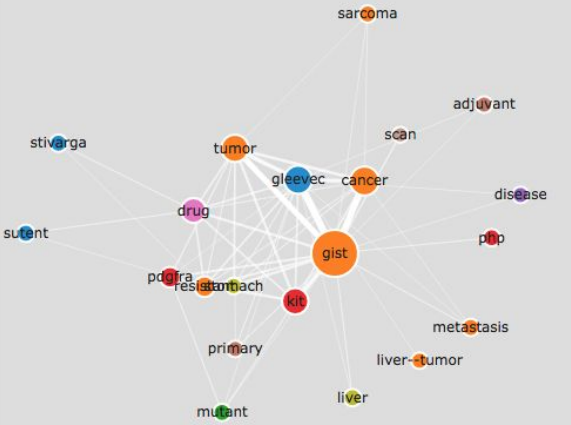
Summarisation: machine learning

# PFM user interface

hereditary  Search

Searched with these words (you can deselect non-relevant words):

hereditary   unlike   heterogeneous: dystrophin   suppressor  
 contributed   genetics   indicates



● Medicines   ● Therapeutic / Preventive  
 ● Gene / Genome   ● Organic Chemical  
 ● Neoplastic Process   ● Diagnostic Procedure

minder detail  meer detail

● 2014-08-25 15:50:52

<http://www.clinicalsarcomaresearch.com/content/4/1/9> This recent article from Italian researchers is in agreement with an earlier article by others about the role of **dystrophin** in **KIT/PDGFR $\alpha$  mutant GIST** for **disease** invasion and **metastasis**. Meanwhile, **dystrophin** dysregulation does not appear to have a similar correlation in metastatic "wild type **GIST**", highlighting that **KIT/PDGFR $\alpha$  mutant GIST** is really a different **disease** than the wild type. Preliminary findings of this small Italian study indicate that the loss of **dystrophin** function (deletions within the gene or loss of the entire gene) is associated with invasiveness and metastatic **GIST**. Perhaps this finding could be a molecular marker in the schemes that estimate risk of recurrence used when determining who needs **adjuvant Gleevec**? In **GIST**, **dystrophin** is downregulated in metastatic **GIST** and **primary** high-risk **GIST**, but not in localized **GIST**, which implies this downregulation is a late event in progression of this **disease**. Finally, **dystrophin** inhibits myogenic **sarcoma** cell migration, invasion, anchorage independence and invadopodia formation; and when downregulated, **dystrophin** restoration inhibits invasiveness and migration in **sarcoma** cell lines. These data validate **dystrophin** as a **tumor suppressor** and likely anti-metastatic factor. Patients with **KIT/PDGFR $\alpha$  mutant GIST** to have higher frequency of DMD deletions in more advanced cases, as DMD loss was seen only in the 5 patients with **metastasis**, whereas 18 out of the 20 patients with localized **disease** wild-type DMD. In our series of 20 patients with **KIT/PDGFR $\alpha$  WT GIST**—including 4 who were SDH deficient and 2 who had quadruple **KIT/PDGFR $\alpha$ /SDH/BRAF-KRAS-NF1** WT did not present **dystrophin** deregulation, even those with **metastasis**, which confirms that **KIT/PDGFR $\alpha$  WT GIST** should be considered a distinct **disease** in molecular background and clinical presentation.

2013-10-19 19:50:37

thanks for adding me. my 58 yr old mother is the **GIST** survivor. she was diagnosed in mid 2011. surgery was done almost immediately, to remove the pecan sized **tumor** at the top of her **stomach**. this month, her **scans** are clear. i'm just wondering how many of you had **GIST** reoccur. also, is it **hereditary**?

● 2013-10-20 17:31:12

**Hereditary GIST** is extremely rare. [http://www.gistsupport.org/ask-the-professional/genetic-factors-in-gist.php?searchresult=1&sstring=hereditary#wb\\_356](http://www.gistsupport.org/ask-the-professional/genetic-factors-in-gist.php?searchresult=1&sstring=hereditary#wb_356)

● 2013-10-20 01:09:34

**Hereditary GIST** is VERY rare. A small **tumor** on the **stomach** usually has the best prognosis. You should look at the pathology report to determine the mitotic rate. Her chances are quite good that it may never come back. <http://www.gistsupport.org/for-new-gist-patients.php>

● 2015-05-17 16:39:27

**PDGFR $\alpha$ -mutant** syndrome <http://www.nature.com/modpathol/journal/vaop/ncurrent/full/modpathol201556a.html> "Germline **PDGFR $\alpha$**  mutations cause multiple **heterogeneous** gastrointestinal mesenchymal **tumors**." "Inflammasome associated fibroid polyps also revealed **PDGFR $\alpha$**  mutations. Subsequently, gastrointestinal CD34+ 'fibrous **tumors**' of uncertain classification were described in a germline **PDGFR $\alpha$ -mutant** context." "In adult **mutants** we detected in the context of fibroid polyps, gastric **GISTs** and gastrointestinal fibrous **tumors** of uncertain nosology." herein) is simplistically considered a form of familial **GIST**, because inflammatory fibroid polyps often prevail. "In this condition, **uracil** dependent familial **GIST** syndromes, if present, **GISTs** are **stomach**-restricted and diffuse Cajal cell hyperplasia is not observed. This restriction of **GISTs** to the **stomach** in **PDGFR $\alpha$ -mutant** syndrome: (i) focuses oncologic attention on gastric masses, as inflammatory fibroid polyps are benign; (ii) supports a selective role of gastric environment for **PDGFR $\alpha$**  mutations to elicit **GISTs**, justifying the known predilection for **stomach** of sporadic **PDGFR $\alpha$ -mutant GISTs**."

2015-02-23 03:44:55

Hello Everyone I just received a message on my facebook page from CBC News here in Ontario. The article caught my eye immediately as the topic was about a rare form of **cancer**. Turns out they were talking about **gastric stomach cancer** and identified a gene as CDH1. They were focusing on a family living in Newfoundland (I think) and that they had lost 7 family members to this **cancer**, and because of this other family members were getting it. Is there any connection between **GIST** and gastric **stomach cancer**?

● 2015-02-23 15:19:02

It's **Hereditary** Diffuse Gastric **Cancer**. No relationship to **GIST**. <http://www.cancer.net/cancer-types/hereditary-diffuse-gastric-cancer>

2013-06-22 17:47:38

I'm curious, who is a member of this group and like me live with **GIST** for over 10 years??

● 2013-06-22 18:59:47

I started **Gleevec** in fall 2000 with an enormous **tumor** load in my **liver**. For some reason I have never developed resistance to **Gleevec**, and **unlike** courageous folks such as John Bissonnet, I've had a relatively easy time with it. It was very bad for the three years before **Gleevec** 1997-2000. **GIST** is a **heterogeneous** collection of **disease** at the molecular level. Evidently, mine though highly metastatic must be a relatively simple **case** overall because it has been well behaved on **Gleevec**. While stories of longevity make us all hopeful, you have to consider the specifics of your case. And some **GISTs** are not as aggressive as others. About 60% of patients diagnosed don't have a recurrence after 10 years following the surgery to remove a solitary **primary tumor**. For the original 147 pts who started **Gleevec** in year 2000, about 20% of us are still on **Gleevec** today. As m

# Voorbeelden (1)

Vraag van een academisch ziekenhuis over al dan niet splitsen van een medicijn dosis (imatinib, personalised medicine voor GIST).

Tekstanalyse van discussieforum geeft het beeld dat splitsen van de dosis (helft 's ochtends, helft bij avondeten) gunstig is met het oog op bijwerkingen. Ook geven patiënten aan baat te hebben bij eten van pure chocolade bij innemen medicatie.

Leidt tot aanpassen van beleid van het ziekenhuis: nu advies om dosis op te splitsen.

Effect van chocola was niet eerder bekend.

# Voorbeelden (2)

- Patiëntenparticipatie project ERASMUS MC: patiënten dragen bij aan onderzoeksagenda
- Co-morbiditeit: patiënten gevonden die twee zeldzame kankers hadden: is dit toeval of is er een verband?

# Vervolg

- Ervaring opdoen, samenwerking met andere kankerpatiëntenorganisaties in binnen- (BVN, Hematon, Melanoom, Van Hippel Lindau) en buitenland
- Combineren met gericht uitvragen met enquêtes
- Analyse levert hypothesen die verder geverifieerd moeten worden
- Samenwerking met oncologen



# Vervolg

- PhD project voor verstevigen van wetenschappelijke basis, validatie, verder ontwikkelen van datamining techniek
- Universiteit van Leiden, LUMC
- Financiering van SIDNFonds
- Start januari 2018

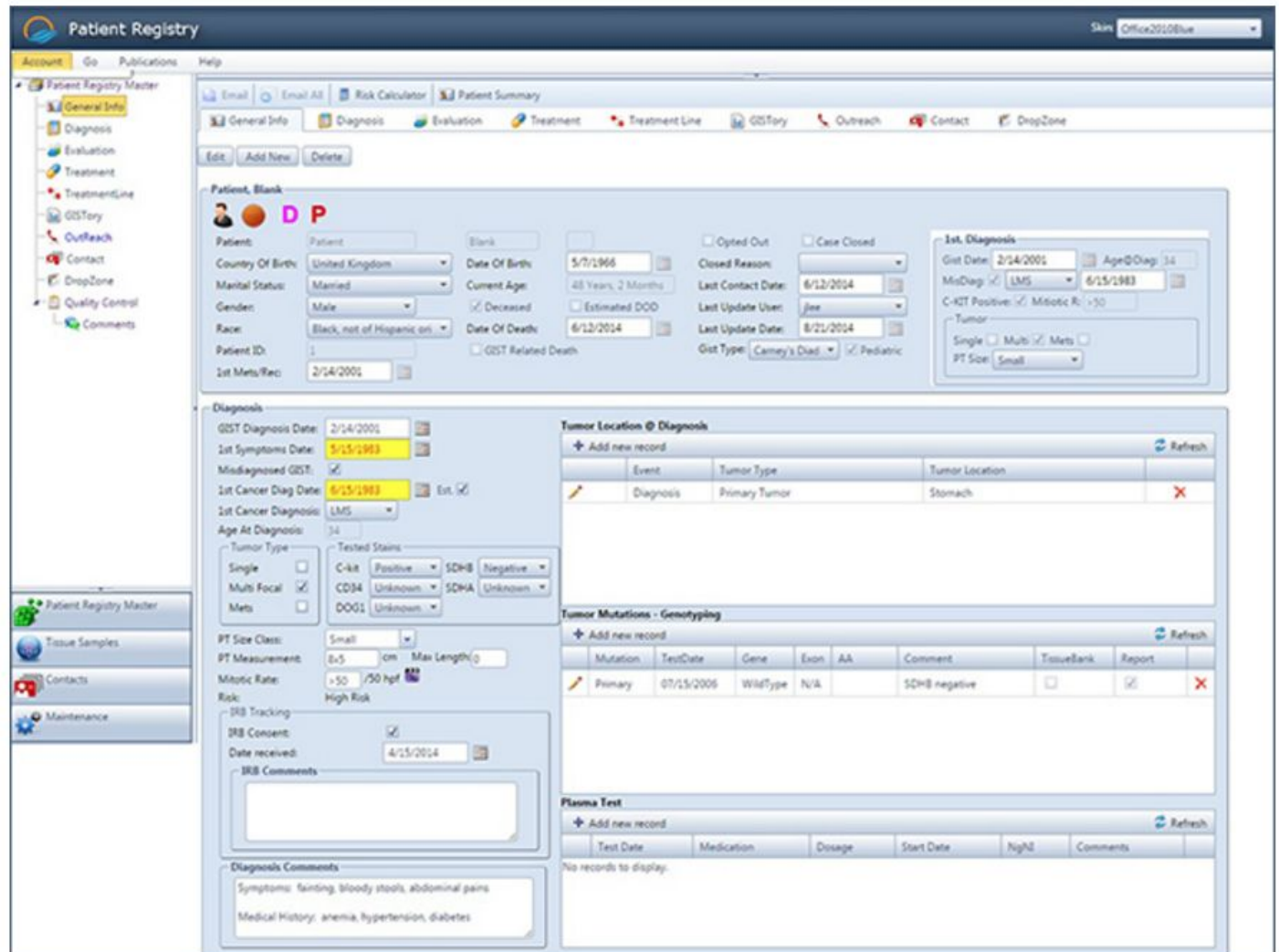
# Uitdagingen

Combineren van de info uit analyse van informele ongestructureerde data uit discussies met:

- PUBMED
- Gestructureerde medische databases van EPD's
- Watson for oncology
- Chatbot interface voor patienten
- combineren met "quantified self"

Liferaft Group

Patient generated  
registry

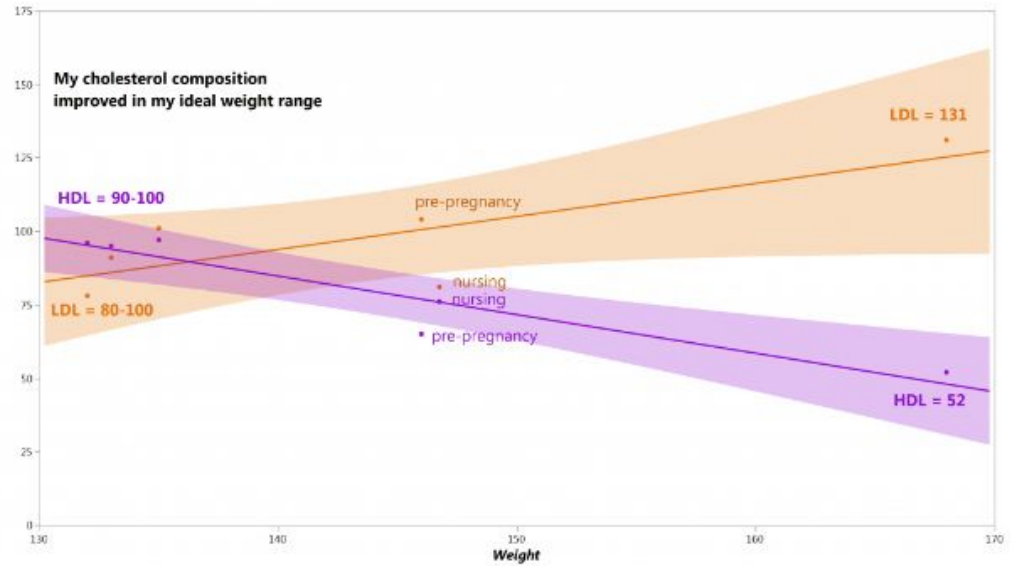
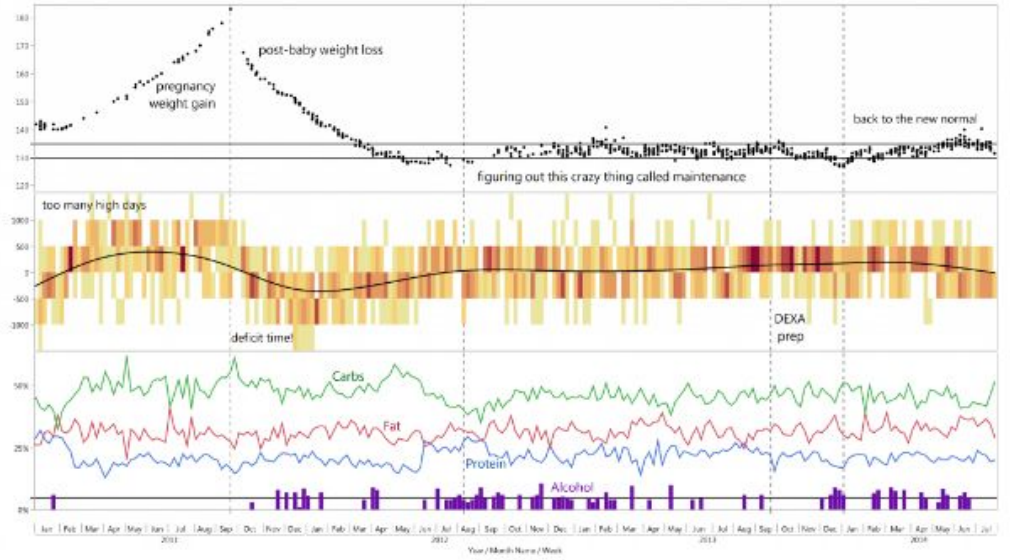


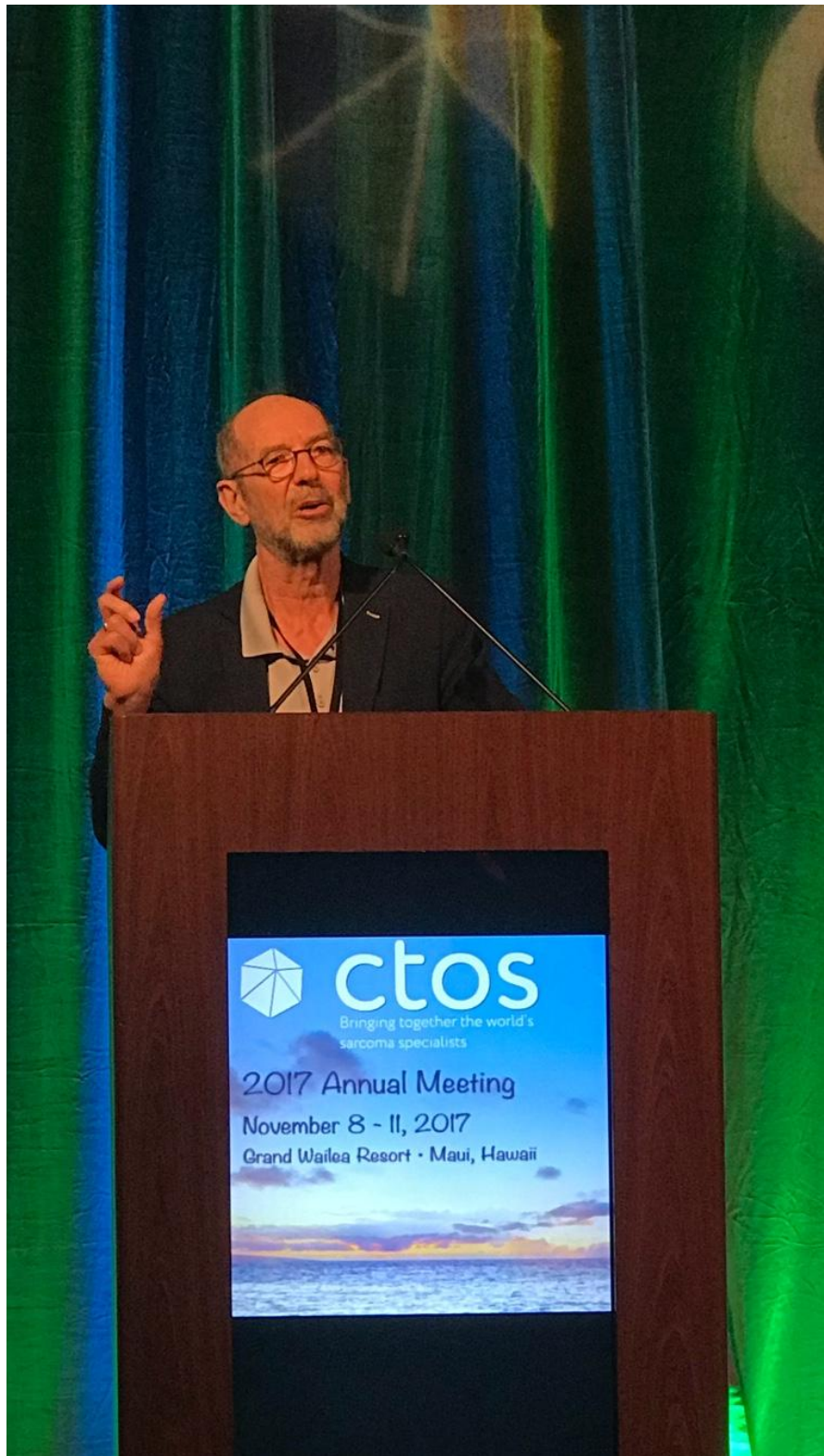
Our goal is simple, a cure. Until that goal is achieved, we must maximize benefit from today's tools. Timely knowledge and information is key to achieving these goals. The Life Raft Group collects this information to allow us to share it with GIST patients and caregivers.

To this end, we have created a unique Patient Registry. All of our information comes directly from patients or caregivers. Using this data we examine questions that are not being answered quickly enough by current trials or that are not being looked at in clinical trials. We also monitor the latest treatments for early indications of a



AliveCor ECG reading displayed on smartphone screen





NOVARTIS

# Conclusie

Tekstmining van discussiefora van patiënten heeft groot potentieel

Informatie gegenereerd door patiënten geeft een nieuwe dimensie aan medisch onderzoek

Belangrijk:

- community
- ervaringsdeskundigheid
- samenwerking met oncologen