



AN INNOVATIVE APPROACH: YPAG

A Young Persons Advisory Group (YPAG) is an organization, composed of **both healthy youths and patients** interested in a health condition or in research, **actively participating** as partners, **advising researchers** and their teams in a full range of activities in various research projects and initiatives.

YPAG ACTIVITIES

- Revision of informative materials
- Support researchers in the design of clinical trials
- Provide advice on social media, innovations and websites

WHO WE ARE ?

YPAG

Young Persons Advisory Group

The first YPAG in Italy!

KIDS BARI and KIDS ALBANIA IS PROMOTED BY



CVBF - Consorzio per Valutazioni Biologiche e Farmacologiche



TEDDY Network



Azienda Ospedaliera Universitaria Policlinico di Bari
Ospedale Pediatrico "Giovanni XXIII"



KIDS ALBANIA

Consorzio per Valutazioni Biologiche e Farmacologiche – Dege e shoqerise se huaj,
Albanian Branch Office



QENDRA SPITALORE UNIVERSITARE
"NËNË TEREZA"

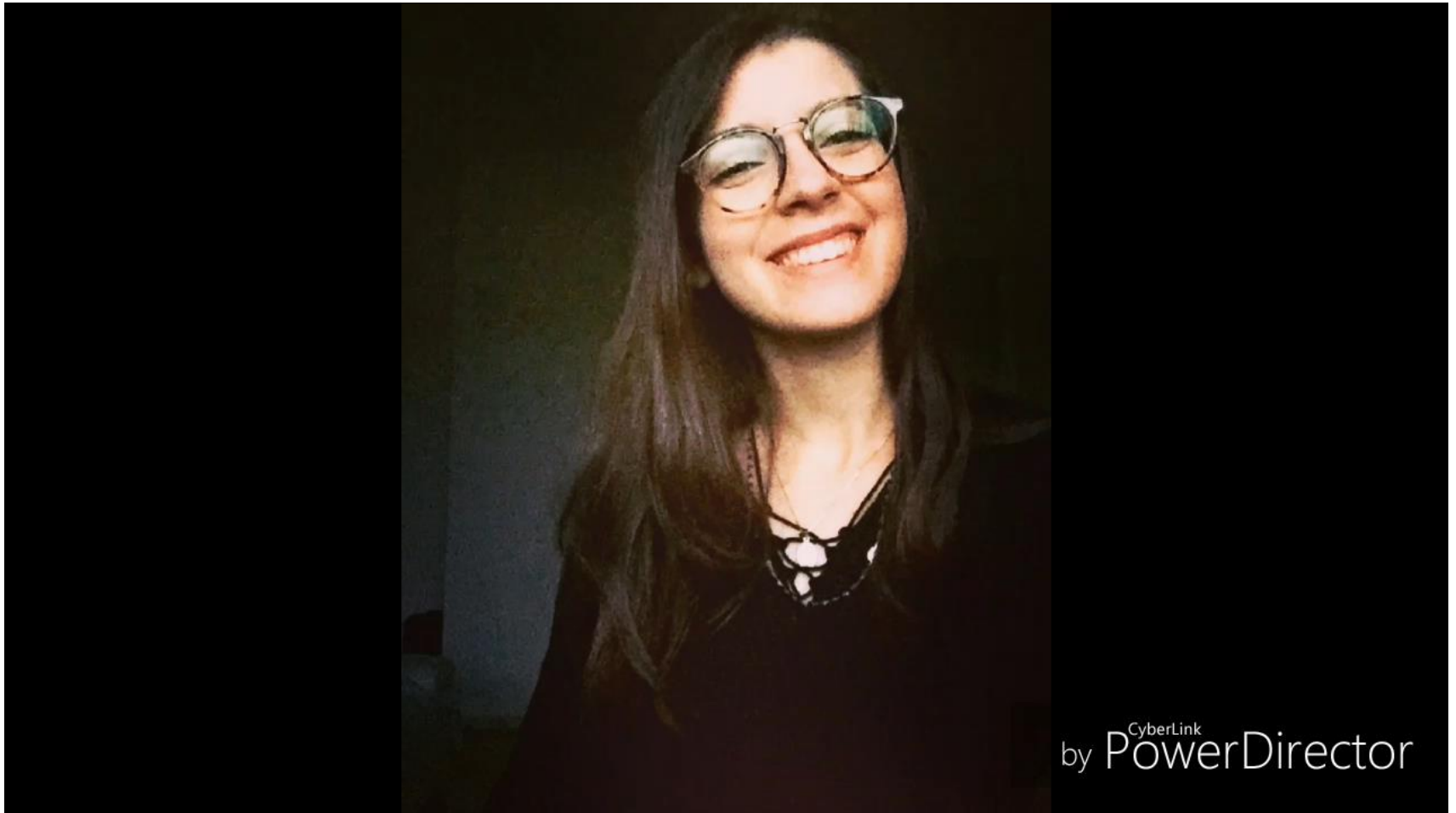
The University Hospital Center "Mother Teresa"



International Children's Advisory Network



WHO WE ARE?



CyberLink
by PowerDirector

OUR TRAINING PLAN

BIOMEDICINE

BASIC RESEARCH

CLINICAL RESEARCH

INNOVATION AND INFORMATION

HUMANIZATION OF HEALTHCARE

BIOMEDICINE

- **WHAT IS A DRUG AND HOW IT WORKS**
- **DIFFERENT TYPES OF DRUGS**
- **SYMPTOMS, DIAGNOSIS, DRUG PRESCRIPTION**
- **ADMINISTRATION (ADME)**
- **SIDE EFFECTS**
- **PAEDIATRIC DRUGS**
- **DIFFERENCE BETWEEN CHILDREN AND ADULTS**



BASIC RESEARCH

- *DRUG DISCOVERY AND DEVELOPMENT*
- *PRECLINICAL RESEARCH*
- *ANIMAL MODELS*
- *PRACTICAL EXAMPLES OF LABORATORY ACTIVITIES*



CLINICAL RESEARCH

- THE IMPORTANCE OF CLINICAL RESEARCH
- CLINICAL RESEARCH PHASES
- CLINICAL STUDY DESIGN
- DIFFERENT TYPES OF CLINICAL STUDIES
- RANDOMIZATION
- RISKS AND BENEFITS
- ETHICS
- INFORMED CONSENT/ASSENT



INNOVATION & INFORMATION

- **INFORMATIVE MATERIAL DESIGN AND DEVELOPMENT OF QUESTIONNAIRE FOR PATIENTS**
- **HELP CHILDREN TO OVERCOME THE FEAR FOR DOCTORS AND HOSPITALS**
- **PATIENT ADVOCACY AND PATIENT EMPOWERMENT**
- **DRUG PACKAGING DESIGN**
- **DESIGN OF MEDICAL DEVICES, APPs AND SERIOUS GAME**
- **COMMUNICATION OF CLINICAL RESEARCH TO LAYPERSONS**



HUMANIZATION OF HEALTHCARE

- RIGHTS OF CHILDREN IN THE HOSPITALS
- PATIENTS ASSOCIATIONS
- FIND OUT THE HOSPITALS: ANALYSIS
- LABORATORY AND DIAGNOSTIC INSTRUMENTS



OUR MISSION

- SUPPORT TO PATIENTS AND PARTICIPANTS IN PAEDIATRIC CLINICAL STUDIES
- INCREASE OF PUBLIC AWARENESS



THIS IS A JOB FOR KIDS!

28 FEBRUARY - RARE DISEASE DAY



**#GiornataMondiale
DelleMalattieRare**

Raramente mi occupo
di rarità... ma è
raro che non mi
occupi di chi è
speciale!

#KidsBari

#WorldRareDiseasesDay

#showyourare

"Sono un uomo, niente di
ciò che è umano,
considero estraneo a me"

È..RARO HUMANUM EST

"Raramente mi occupo di
rarità... ma è raro che non mi
occupi di chi è speciale"

#ShowYouRare
#GiornataMondialeDelleMalattieRare
#WorldRareDiseasesDay
#kidsBari



THIS IS A JOB FOR KIDS!



8 MARCH - WORLD KIDNEY DAY

#giornatamondialedeirene

Giovedì 8 marzo 2018

Introduce un giorno per niente sempliciotto!

Oggi è una giornata

Realmente importante,

Non deve essere snobbata

Anche se non sembra rilevante.

Tratta un argomento molto caro,

Anche se a molta gente è ignaro.

Meramente celebriamo questo

Onorevole avvenimento

Notevole come un patrimonio dell'Unesco

Discusso per il suo argomento.

Infatti, oggi lodiamo e

Acclamiamo

La giornata mondiale del rene,

Elemento che nelle fosse lombari risiede.

Due milioni,

Ecco il numero di pazienti in Italia che soffrono

Le malattie renali.

Ringraziamo

E nutriamo molto rispetto

Nei confronti di chi

Esprime interesse per questo evento, oggi prediletto.

#kidsbari



#GIORNATAMONDIALEDEIRENE

Ringraziamo

Con il cuor **E**

Nostri

Edici

#KIDSBARI

THIS IS A JOB FOR KIDS!

SURVEY “Pediatric Devices Survey”



by EPTRI

European Paediatric Translational Research



SURVEY “Factors Impacting Paediatric Clinical Studies Preparedness”

by Enpr-EMA (European Network of Paediatric Research at EMA)



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

THIS IS A JOB FOR KIDS!

EPTRI MEETING , MADRID , MINISTRY OF HEALTH



OUR FUTURE PROJECTS

SERIOUS GAME

WEB SITE AND BLOG

VOLUNTEER ACTIVITIES

COLLECT FUNDS

AWARNESS CAMPAIGNS

PARTICIPATION IN SCIENTIFIC MEETING

PARTICIPATION TO ONLINE QUESTIONNAIRE

PARTICIPATION IN EUROPEAN PROJECTS

TO FIND OUT MORE

www.cvbf.net

www.teddynetwork.net

THANK YOU!

