

# Perinatal Hospice – experience of the Warsaw Hospice for Children Foundation

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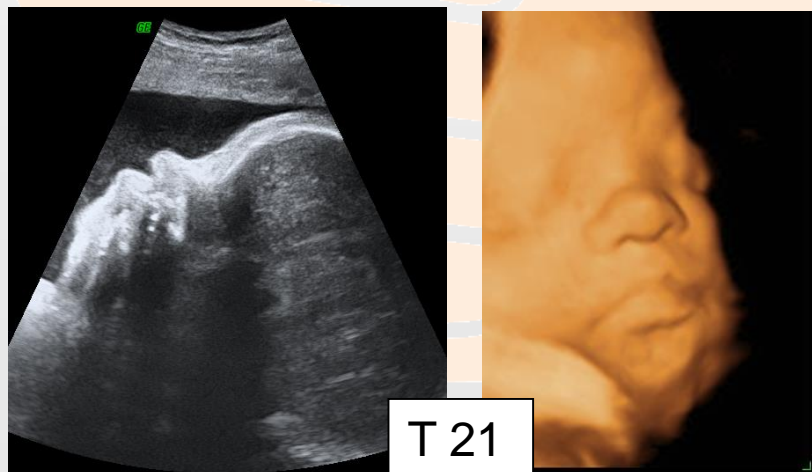
Perinatal palliative care is ensuring comprehensive support for the parents of fetuses and newborns with lethal defects and care for newborns with these defects, aimed at ensuring comfort and protection from persistent therapy.

It encompasses symptom control in the child and psychological, social and spiritual support for the parents, including support during bereavement.

The child can be cared for in a neonatal ward or at home by the parents and hospice if the child survives delivery and is discharged from the hospital.

# Lethal defect – definition

- (1) a developmental anomaly that leads to spontaneous abortion, immature delivery, or intrauterine death;
- (2) a developmental anomaly leading to the premature death of a live-born child, irrespective of any therapy that may be applied;
- (3) a developmental anomaly classified as grounds for legal abortion



Dangel T.



Alternative to abortion – for those who want to continue the pregnancy even if the diagnosis is life-limited condition and prognosis is bad

To support parents during emotional turmoil which is normal and common in their situation (complicated pregnancy)

To help to survive the uncertain time of the uncertain prognosis

- To discuss the choice after delivery: persistent intensive care or palliative care
- To prepare the hospital staff for delivery – and to give them information about the parents' decision for the future treatment
- To contact newly diagnosed parent with other couple who walked the same path



## **Consultant in perinatology and perinatal cardiology**

- medical counselling
- characteristic of disease
- life time expectancy

## **Psychologist** – perinatal consultation

**Obstetrician** – full care in the Complicated Pregnancy Clinic; delivery planning

**Neonatologist** – care after delivery, necessary and unnecessary procedures

**Palliative care specialist** – home care after live delivery

# Perinatal Hospice

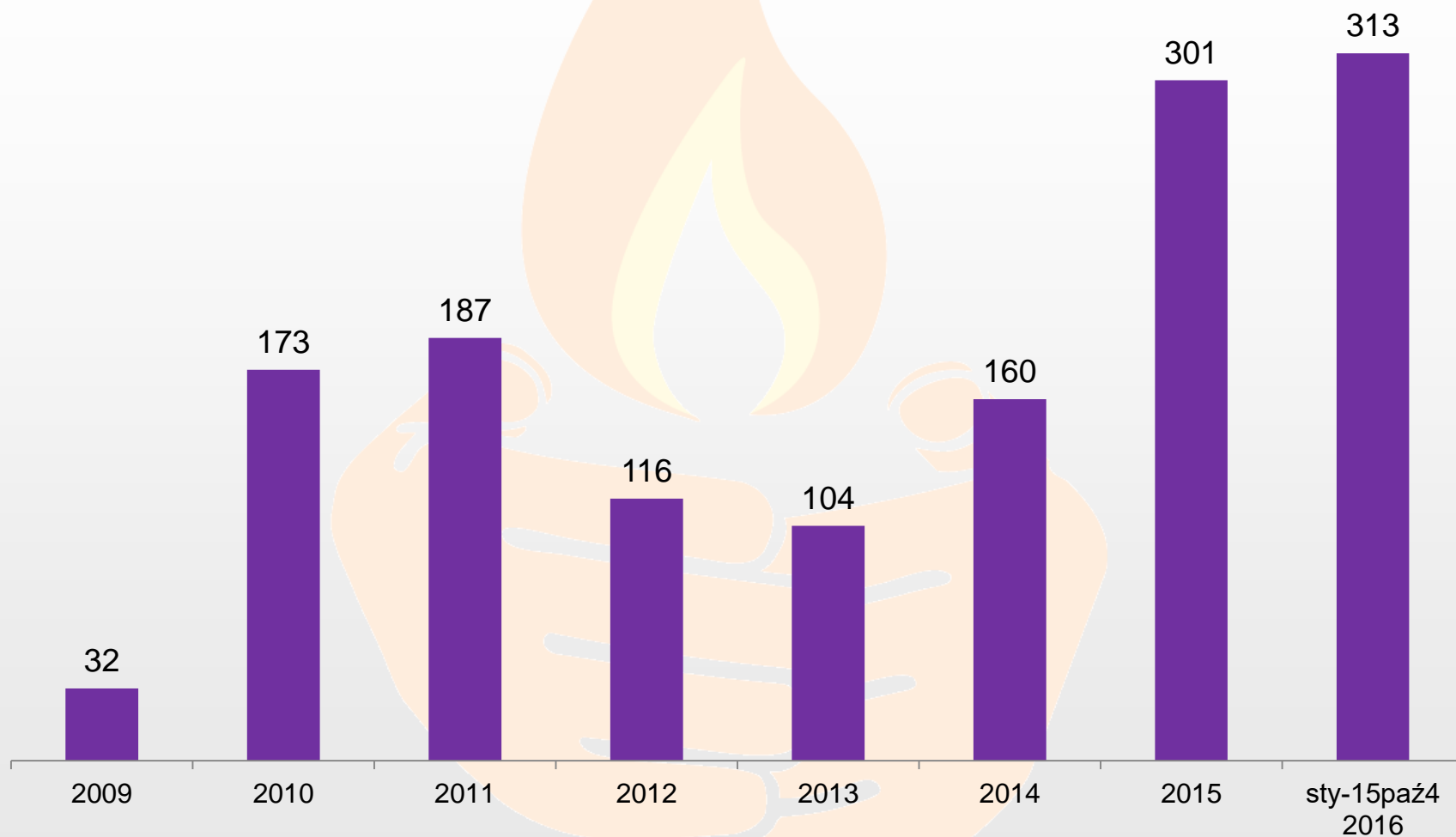
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March 1st, 2012 – the agreement with the Bielanski Hospital (Warsaw, Poland) – introduction of the psychological consultation for parents who want to terminate pregnancy

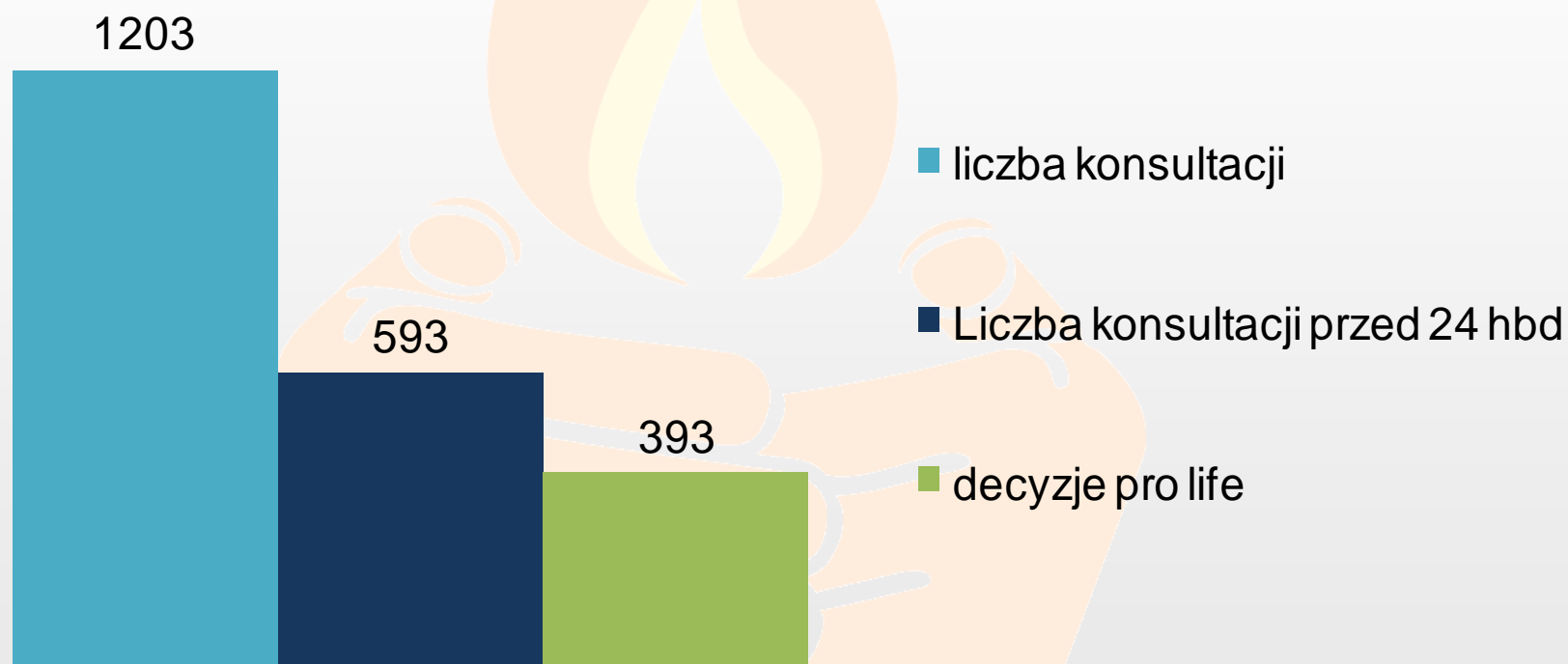




# The numbers of psychological consultations (Agatowa & hospitals)



# Consultations & decisions 2009-2016 in Agatowa Clinic



# The beginning

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Hospice for Children – Warsaw, 1994

First prenatally diagnosed patient - Edwards syndrom

## **Wioletta**

Born 18.12.1998

Admitted 15.01.1999

Died 23.01.1999

9 days under hospice care



## Hospice patients diagnosed prenatally (n=46)

- Trisomy 18 20
- Trisomy 13 5
- Congenital malformation of brain 6
- Other chromosomal abnormalities 6
- Other 9



T 18

# Perinatal Hospice – parents' emotions

Shock and disbelieve

Anger (with God, doctors, nature)

Guilt (sometimes connected with looking for understanding)

Shame

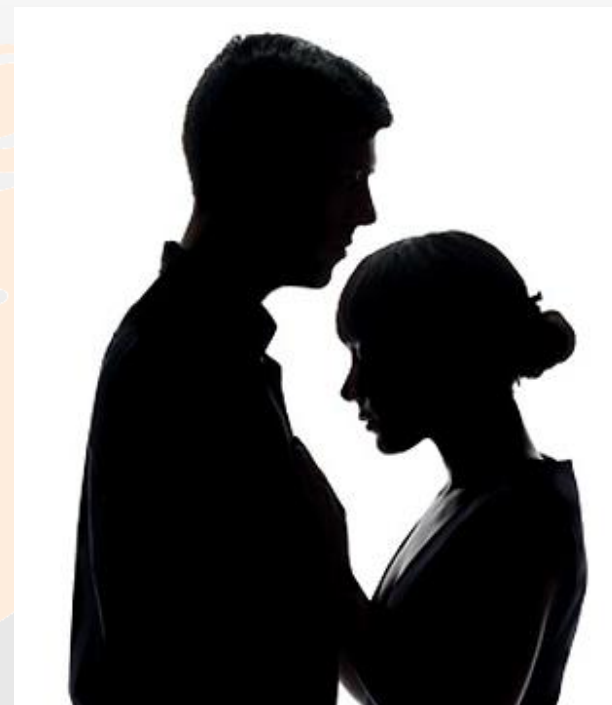
Lower self-esteem

Withdrawal

Sense of injustice

Loneliness and depression

Distancing from the unborn baby



# Perinatal hospice organisation



Admission to hospice program

Home care

Bereavement support





**Stanęliście Państwo w obliczu  
trudnej decyzji:  
usunąć ciążę czy ją utrzymać?**

**Jeśli nie jesteście Państwo  
pewni co zrobić i chcielibyście  
przedyskutować wszystkie za  
i przeciw każdej z opcji, możecie  
umówić się na spotkanie  
z doświadczonym psychologiem.**

*Szczegóły na odwrocie*



**Fundacja Warszawskie  
Hospicjum dla Dzieci**

niesie pomoc  
rodzinom w sytuacji  
niepomyślnej diagnozy  
u ich nienarodzonego  
dziecka.

**Aby umówić się na bezpłatną  
konsultację psychologa, pro-  
simy o kontakt pod numerem  
tel.:**

**504 144 140  
509 797 324  
226 781 611**



**Thank you**