Challenge of Thalassemia Management in Indonesia

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Purwokerto Map
Challenge in Therapy

1. Transfusion center and Insurance issues
   • Total patients registered: around 9000 patients.
   • Carrier frequency 3-15% → 2500-3500 patients born/year
   • Total residents: 260 million → (mostly unregistered or under diagnosed).
   • Total districts in Indonesia: 512, Transfusion center: <30 (only cover <10% from the total)
   • Covered by National Health Insurance (Number 4 in budget). 215 Billion IDR jump to 476 Billion IDR in just 2 years (2014-2016).

2. Availability of medicines
   • Insurance cover blood transfusion and iron chelator.
   • Insurance use INA-CBGs protocol. Sometime it cause underdose and reflect to uncontrolled complication.
   • Not every hospital or transfusion center has iron chelator.
   • Monitoring availability: ferritin level, hepatitis B/C but only some centers can performe.
3. Molecular aspects

• 2012-2017 some new mutations have been found: IVS1-2, Cd123/124/125 (ACCCCACC), Cd40 (G), CAP +1 (A>C)

• DNA test centers, available in some Medical Faculty Institution: UI (RSCM), USU, UNAIR, UNDIP, UNHAS, UGM, UNPAD, UNSOED

• EIJKMAN Institute

• Awareness of clinicians to use mutation data

Personalized medicine?

Pustika Amalia, 2012
Prevention

1. Formal regulations
   - National Health Insurance (BPJS) start form 2014. Curative only.
2. Diagnostic issues
   • Equipments: Lack of quantity and distribution (Blood analysis and Hb Elfo devices)
     not in every transfusion center
     only in some big cities.
   • Experts: lack of distribution.
     Patologist and Pedicatricians
   • Prenatal Diagnosis: only 1 or 2 hospitals (Jakarta and Bandung ?)
     Bandung has performed NIPT ?

3. Community awareness
   • Lack of mass education for layman and (even in health personels).
     Some of the patients come from health personal’s children
   • Stigmatization to thalassemia patients or over protection from family.
Seminar Pencegahan Thalassaemia
untuk Tim Penggerak PKK Se Kabupaten Banyumas

BANYUMAS GOES TO ZERO

RAPATKAN BARISAN,
SATUKAN LANGKAH MENUJU SATU TUJUAN

"BANYUMAS BEBAS THALASSAEMIA"

(keterangan: "tulisan di layar papan besar di depan dinding)
“Banyumas Goes to Zero 2030”:
- local prevention program
- voluntary program held by thalassemia team of Banyumas.

The goal:
1. provide a network connection to give readiness of screening test and prevention program.
2. Public voluntary screening test

Activities:
Connect local resources into the thalassemia prevention program

1. Local Health Department: provide primer health resources (Puskesmas) as center information and first layer screening of thalassemia.
Almost 8 of 36 primer health facilities have been trained and equipped with perifer blood smear and hemoglobin analyzer.

Training for: MD, technicians, and midwife
Referal system: Puskesmas -- > Banyumas Hospital

Education department:
- Curriculum in senior high school
- Batamas (Sahabat Thalassemia Banyumas)
  Peer counseling
- Boy scout and Red cross organization
routine mass education:
- senior high school
- marriage registrar
- PKK (Family Welfare Movement)
Faculty and Hospital
1. Advocating the foundation on the optimal curative managements
2. Spreading the public awareness.
   - Seminar and symposium
   - leaflet, banner, etc
3. complete the diagnostic devices : Blood analysis, Hb Elfo (Sebia), DNA analysis.
INSTALASI PELAYANAN THALASEMIA TERPADU
NGO:

- Mass screening (Rotary and others)
  
  Primer family: 54% carrier, students and public: 8% carrier.

Local government:

- Future plan: local prevention regulation
The End