

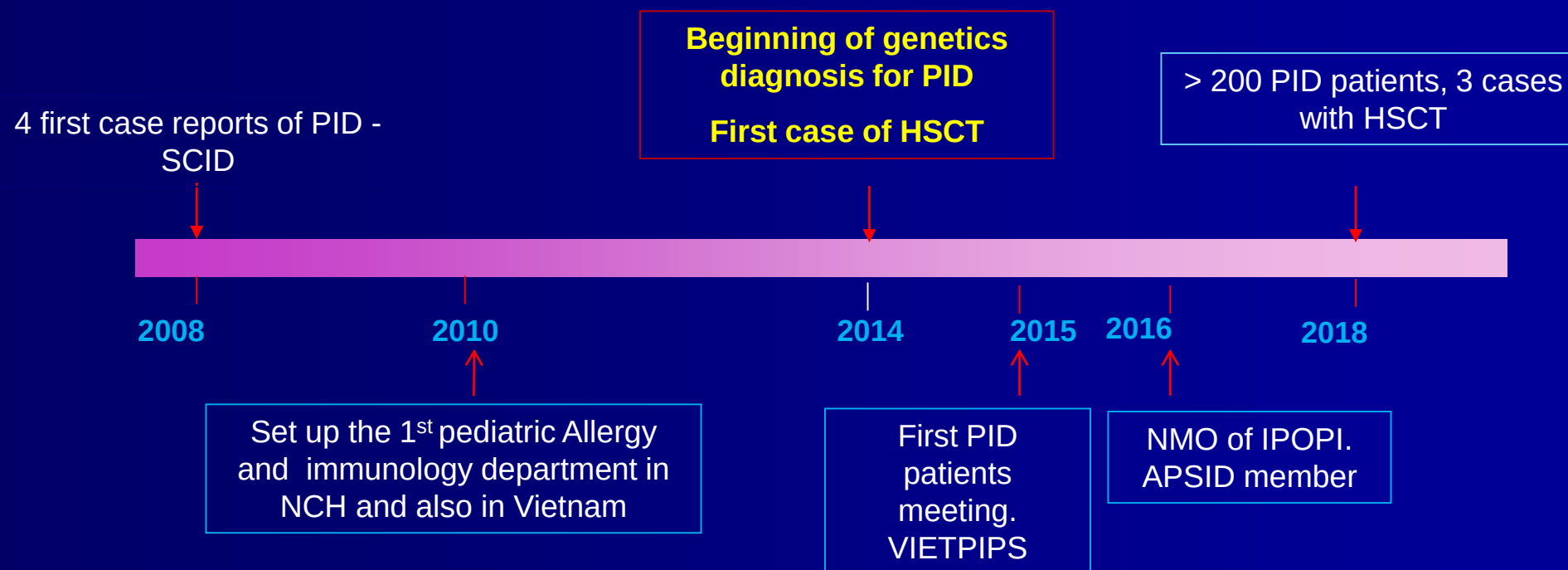
Primary Immunodeficiency in Vietnam

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Head of Allergy and Immunology Department*

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1. **The establishment of department to manage PID in National Children's Hospital**
2. **Diagnosis status in Vietnam**
3. **Management of PID in Vietnam**
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Establishment Department



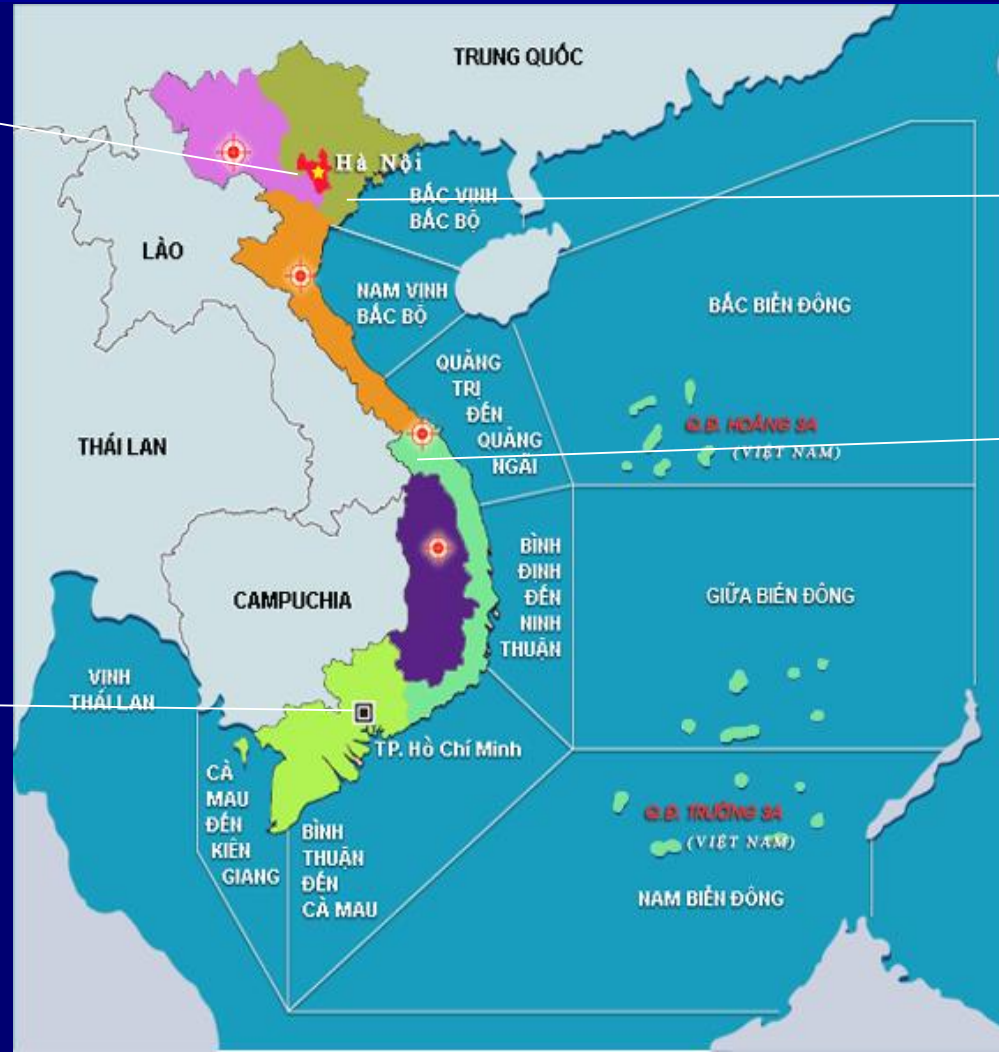
Some PID units in Vietnam

Hanoi

1. National Hospital of Pediatrics (2010)
2. & Bach Mai Hospital (1980)

Ho Chi Minh:

1. Pediatric Hospital No. 1
2. Pediatric Hospital No. 2
3. City Pediatric Hospital
4. Cho Ray Hospital
5. University of Medicine and Pharmacy in Hochiminh



Haiphong:

1. Haiphong General Hospital
2. Green Hospital

Hue Area:

1. Hue Central Hospital

Danang Area:

1. Danang Hospital of Women and Children

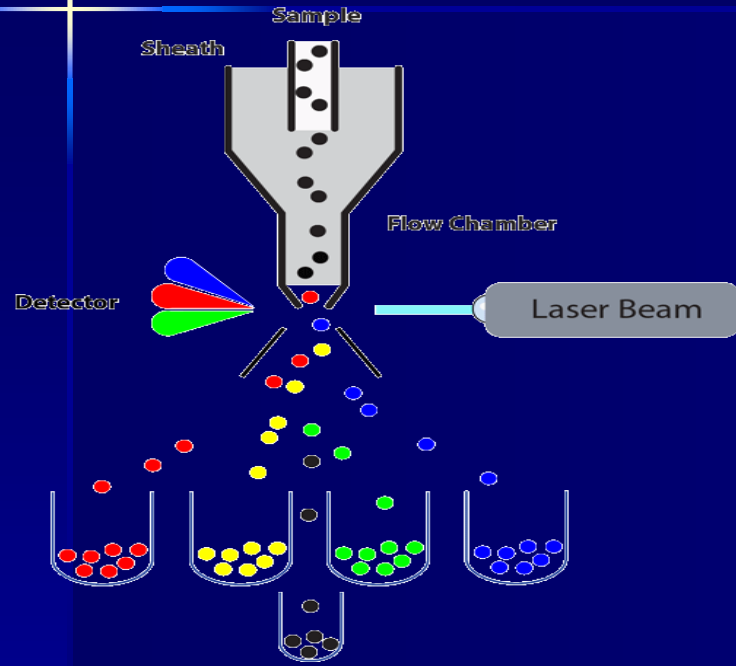
Establishment PID network in Vietnam

1. Medical Education programs for general doctors to be recognize suspected PID patients in provinces of Vietnam (CME)
2. Support from US/Europe/Asia Pacific experts
3. Develop new units based on geographic area
4. Setting up diagnosis centers (NCH)

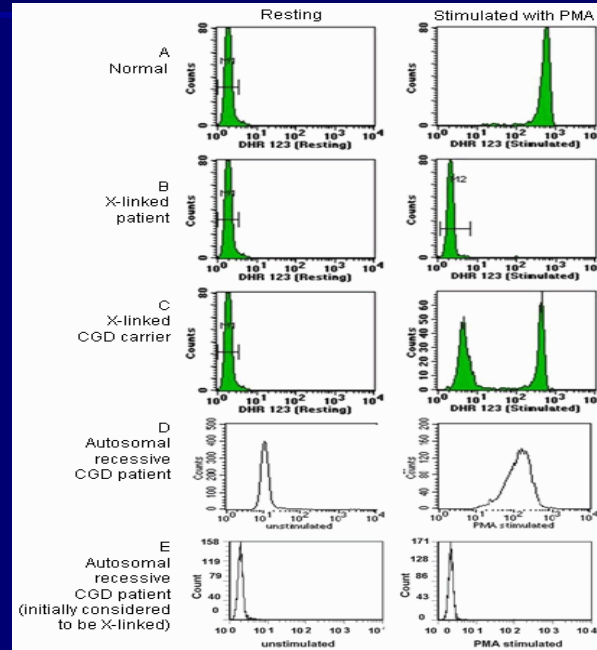
PID Diagnosis

1. **Family history**
2. **Patients' history**
3. **Clinical manifestations**
4. **Common laboratory test**
5. **Cytometry technology**
6. **Genetic encoding**

Laboratory



Flow cytometry



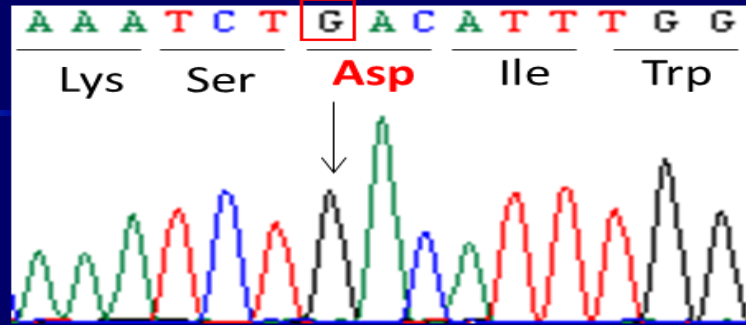
Phagocytic killing test



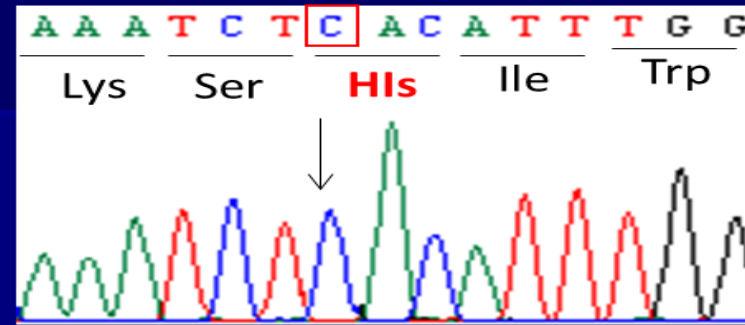
Genetic testing

GEN *BTK* in XLA (XLA-01)

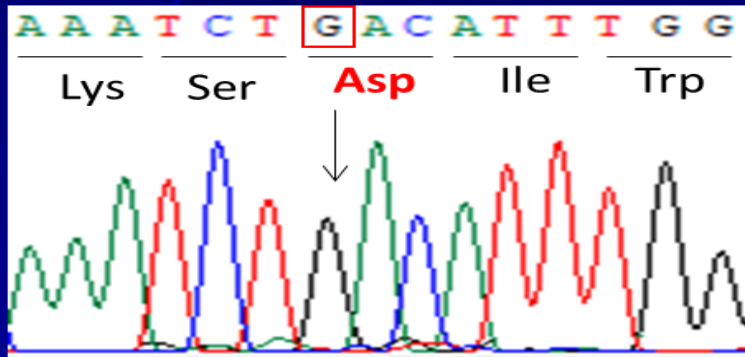
c.1735G>C
p.D579H



Người bình thường

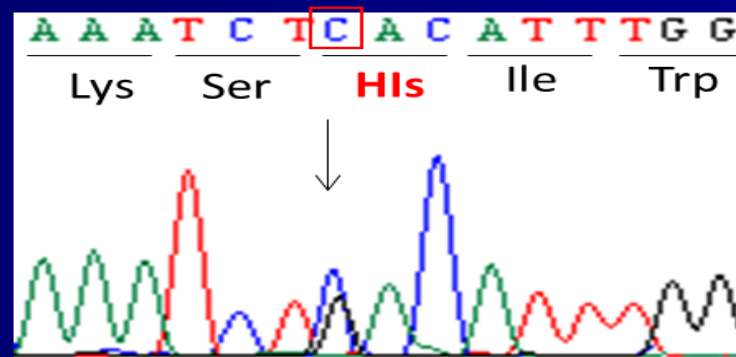


Bệnh nhân XLA-01



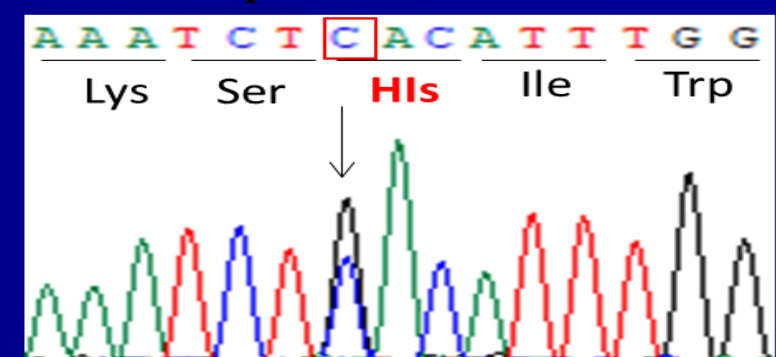
Bố bệnh nhân XLA-01

c.1735G>C
p.D579H



Mẹ bệnh nhân XLA-01

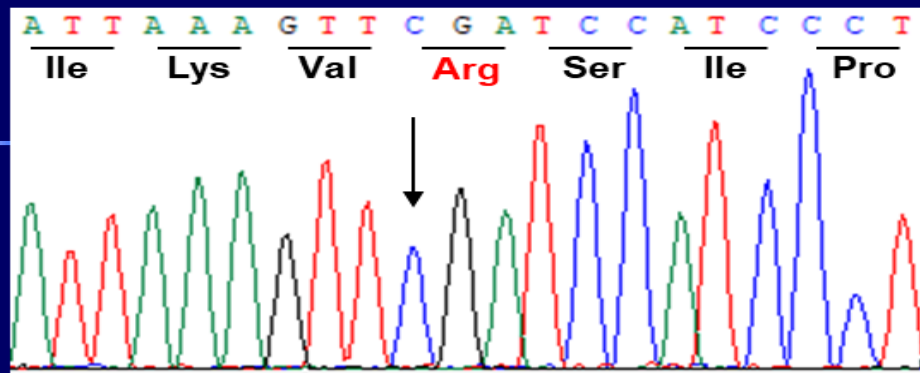
c.1735G>C
p.D579H



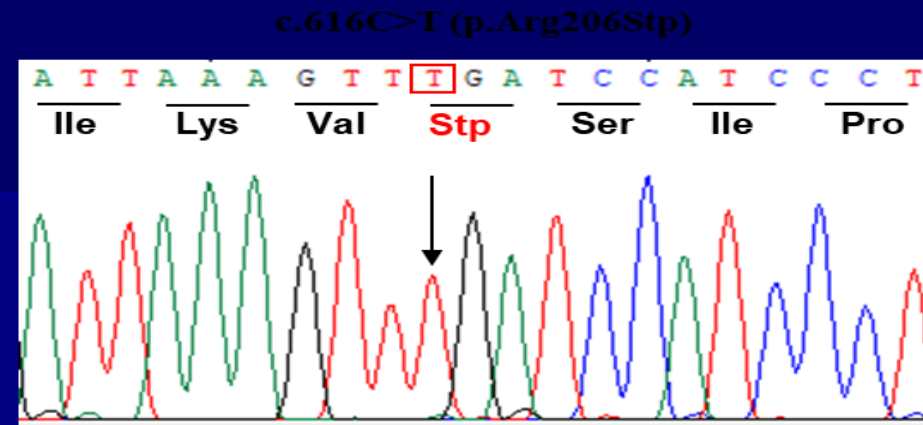
Chị gái bệnh nhân XLA-01

- Đột biến mới, tại nucleotide số 1735, Guanine ->Cytosine, a.amin ở vị trí 579, Axit amin Aspartic-> Histidine.
- Con trai có đột biến được di truyền từ mẹ, chị gái bệnh nhân có dị hợp tử đột, bố không có đột biến.

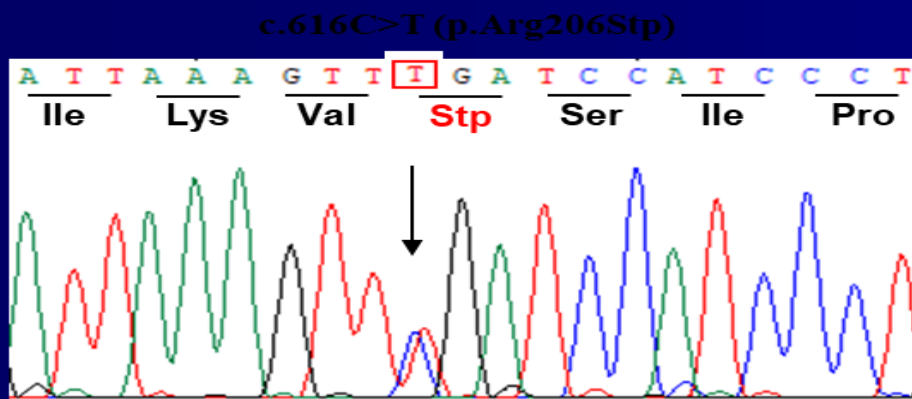
GEN *IL7R* in SCID (SCID-03)



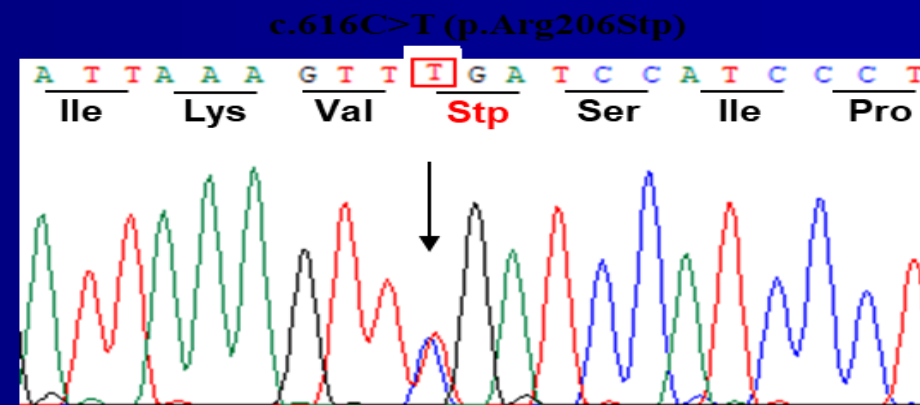
Người bình thường



Bệnh nhân SCID-03



Bố bệnh nhân SCID-03

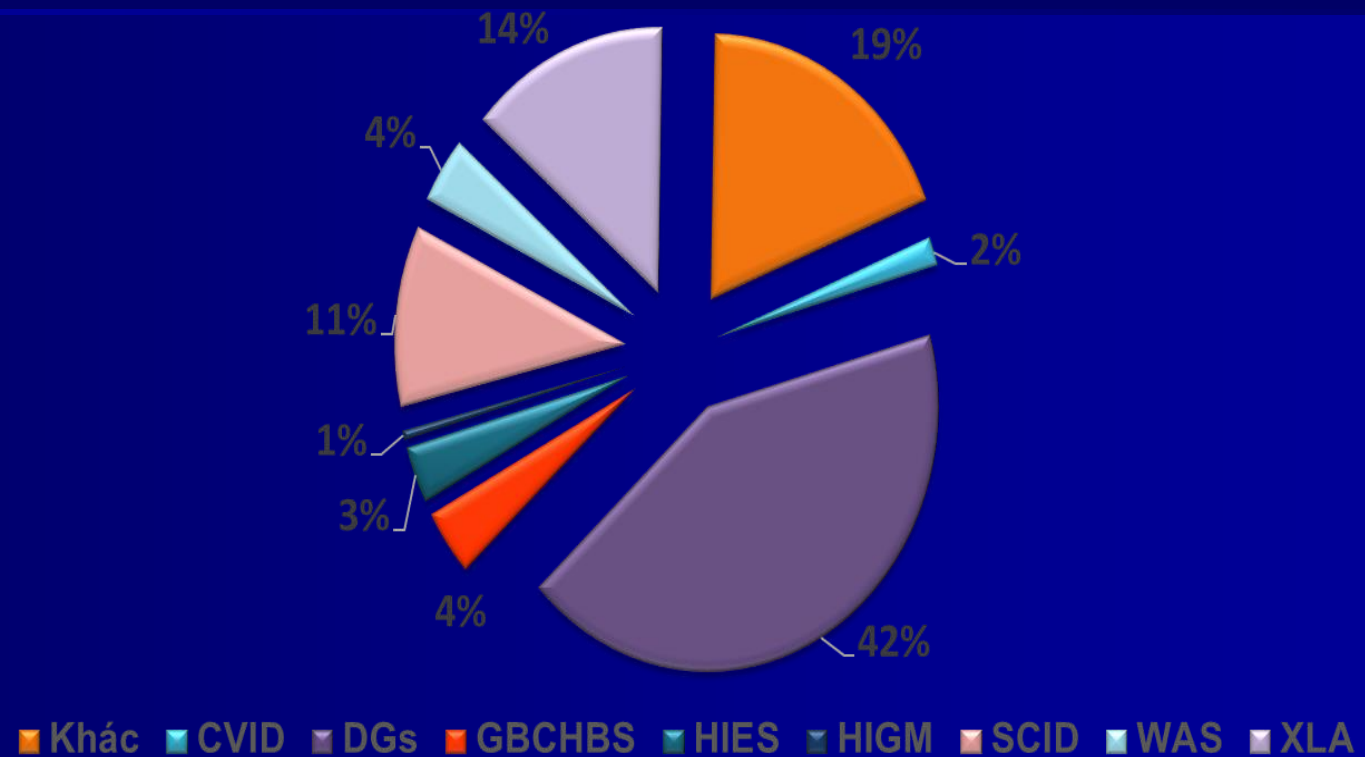


Mẹ bệnh nhân SCID-03

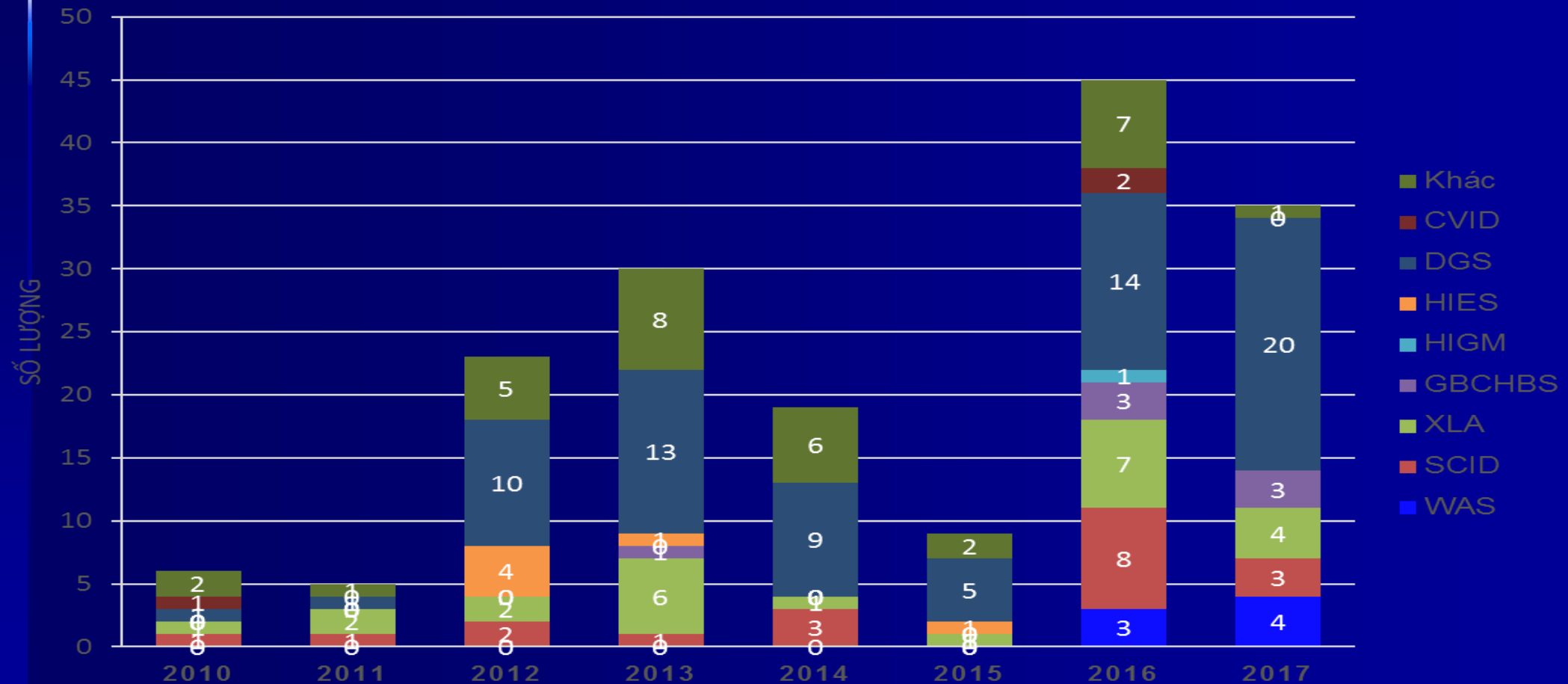
- Tại nucleotide số 616, C ->T, axit amin ở vị trí 206 Arginine ->codon kết thúc --> tạo mã kết thúc sớm.
- Bệnh nhân đồng hợp tử đột biến này di truyền từ bố và mẹ.

PID patients in National Children's Hospital during 8 years (2010-2017)

172 patients

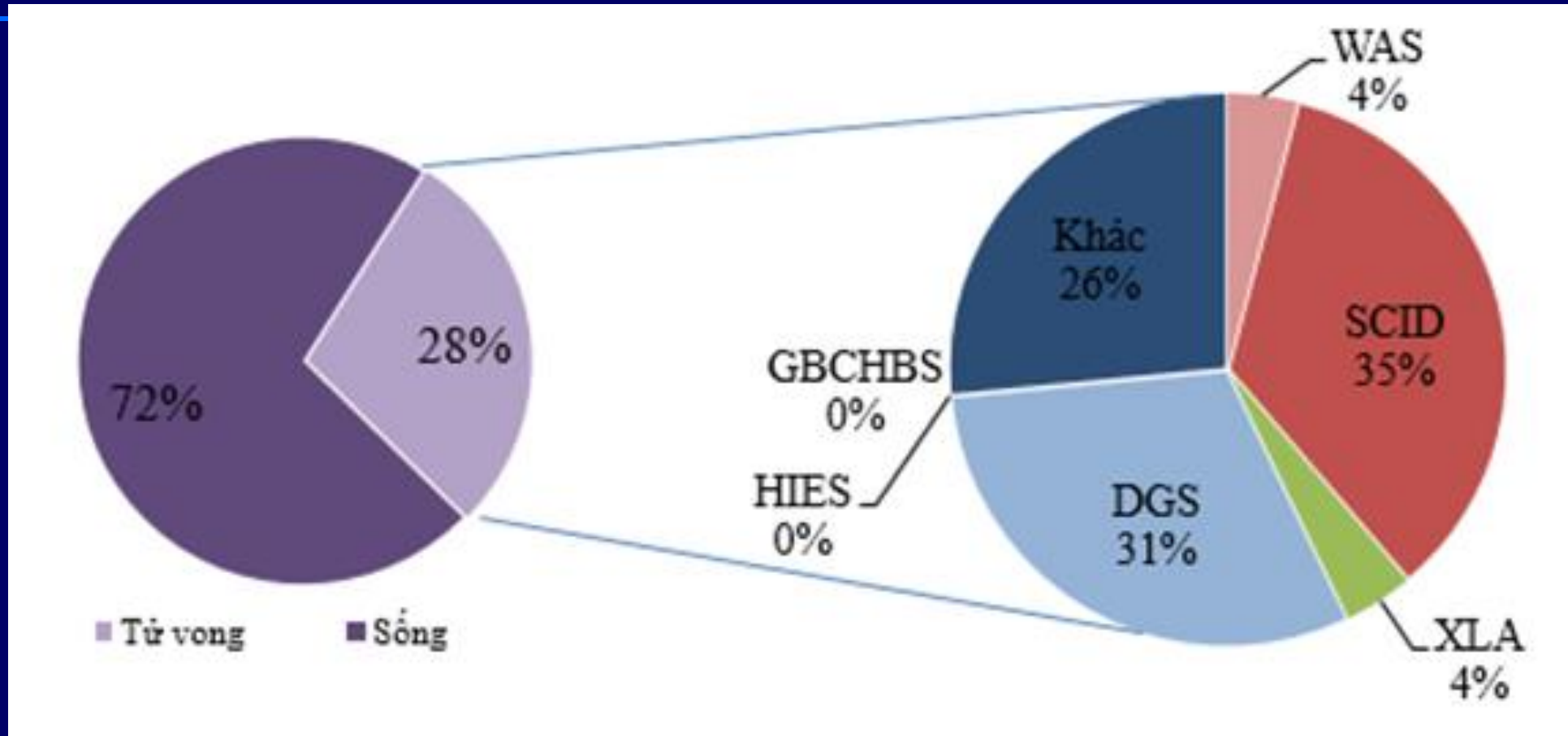


PID patients in National Children's Hospital during 8 years



PID patients in National Children's Hospital during 8 years

Mortality



Management PID in Vietnam

1. **Antibiotics for treatment infections**
2. **IgG replacement**
3. **Bone marrow transplantation (haploidentical)**
4. **Patients' club such as a VIETPOPI to help PID community sharing experience in taking care of PID (IPOPI support in print some educational books)**

IgG Replacement

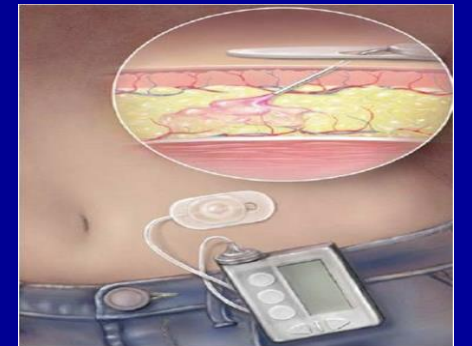
1. **IVIG**

1. Start from 2008 in Vietnam
2. There are certain disadvantage: time, burden for healthcare system, burden for parents, systematic side effects
3. Have to use antibiotics for prevention of infection
4. Patients feel not health, especially in last 10 days before next transfusion



2. **SCIG**

1. Trial for SCIG from 2017
2. More advantages



Comparison of IVIg and SCIg treatment^{1,2}

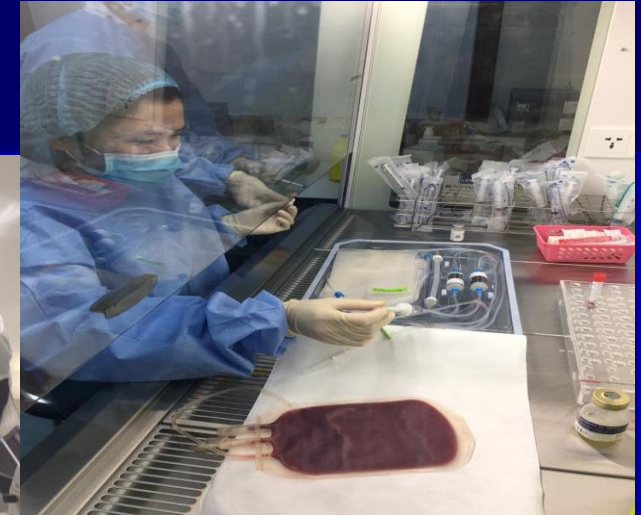
Attribute	IVIg	SCIg
Infusion frequency and duration	Longer infusions once every 3 to 4 weeks	Shorter but more frequent (typically weekly) infusions
Volume infused	Typically larger volumes in comparison to SCIg*	Typically smaller volumes in comparison to IVIG*
Administration	Venous access required	Venous access not required
Absorption	Directly absorbed into blood	Gradual absorption through lymphatics
IgG levels	Initial peak followed by trough towards end of dose	Consistent IgG levels maintained with weekly infusions
Setting	Typically in clinic/hospital	Home therapy, allows active patient participation
Adverse events	Systemic	Local

•Infusion volume is dependent on concentration of IgG product and frequency of infusion

1. Berger M. *Clin Immunol* 2004;112:1-7

2. Ballou M et al. *Clin Exp Immunol* 2009;158(Suppl 1):14-22

Bone marrow transplantation (haploidentical)



Bone marrow transplantation (haploidentical)



CHALLENGES in PID

1. **Missed diagnosis:**
 - There is no PID in Vietnam
 - Can not diagnose PID
 - Can not treat
2. **Treatment cost is burden**
3. **No National register**

Solution for PID: Diagnosis

- 1. To implement more education for immunology experts and other medical doctors in big cities and nationwide (rural provinces)**
- 2. To open more diagnose center: experts and facility**

Solution for PID: National register

- 1. We need to establish National network for registration**
- 2. Need to invest for soft ware, education health people for the first signs or symptoms suspected**
- 3. Connecting to neighbor countries and international centers**

Solution for PID: Insurance Policy

- 1. Treatment for PID is costly**
- 2. Healthcare insurance just cover 80%, patients have to pay 20% but it is challenge for their family**
- 3. Insurance system is not applied reimbursement for all hospitals with high cost products**

Solution for PID: Funding in community

- 1. This is a critical factor to help PID patients**
- 2. Long journey to work with health authority and community**

SEAPID (South East Asia PID) Network

26 Jan 2015

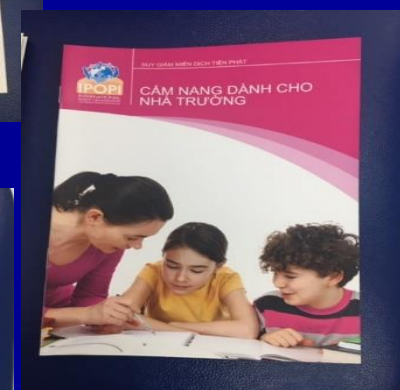
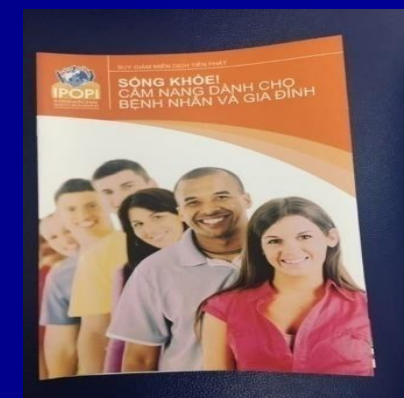
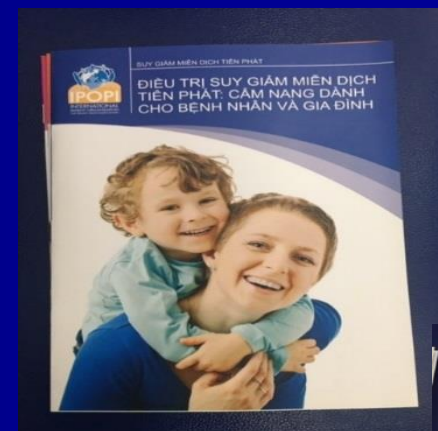
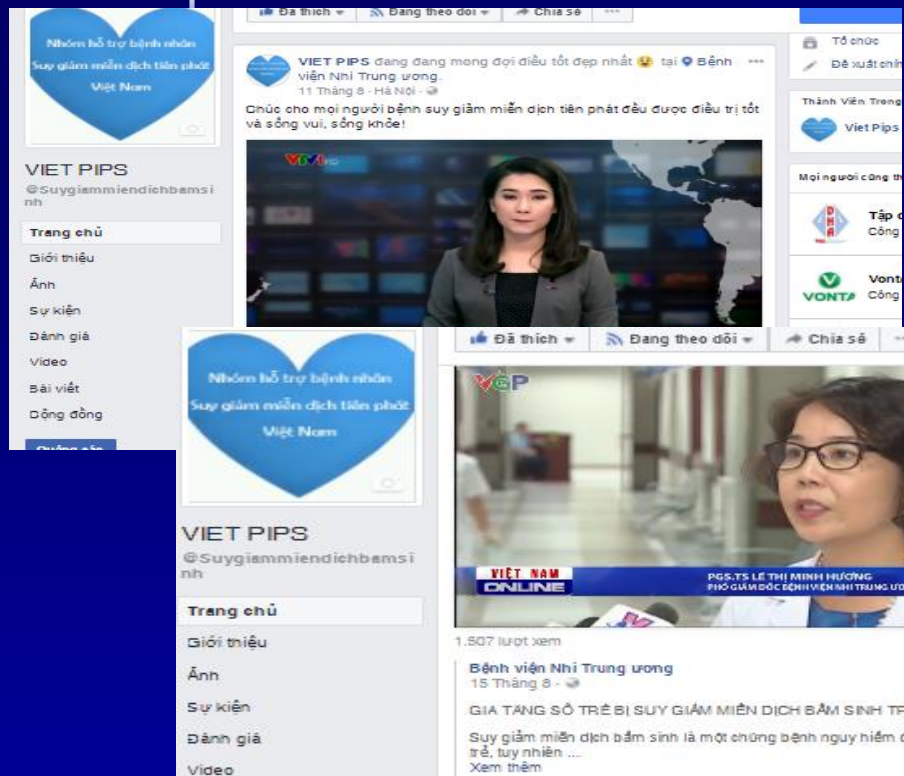


6 Founders: SEAPID network

Thailand
Malaysia
Singapore
Vietnam
Indonesia
The Philippines



<https://www.facebook.com/Suygiammiendichbamsinh/>





Second VietPOPI meeting for PID patients and doctors

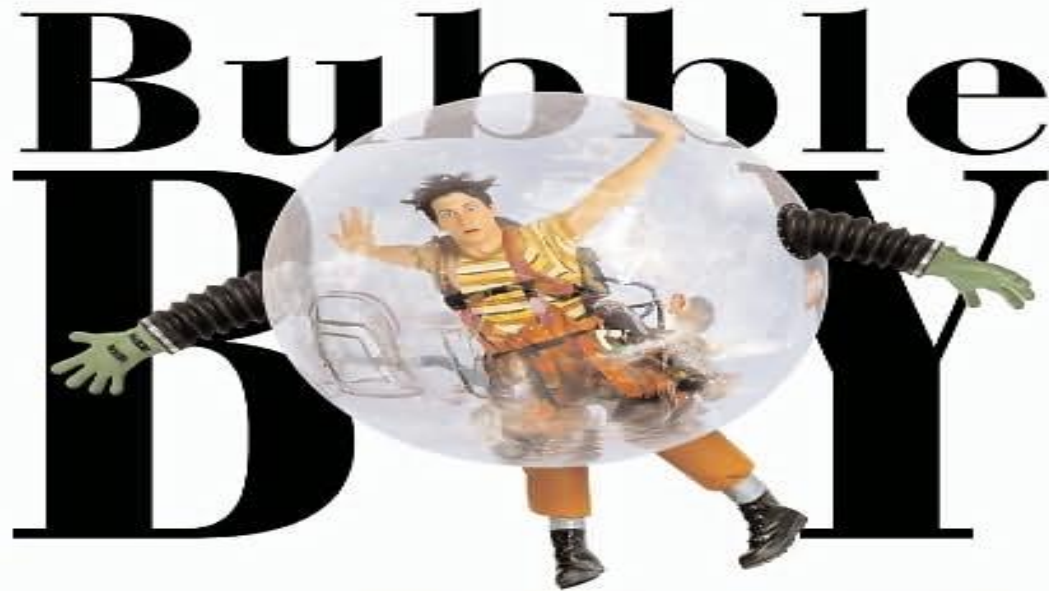


JMF (Jeffrey Model Foundation) Hanoi Kids Day



World PI week in Vietnam

A JOURNEY OF 2,755.8 MILES
BEGINS WITH A SINGLE BOUNCE.



LIFE IS AN ADVENTURE. DON'T BLOW IT.

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THANK YOU