

# The Role of Non-Governmental Organization in Preterm Infant Follow-up

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**10.6%**

**The preterm birth  
rate in Taiwan in  
2022.**



**15,000**

**The number of  
premature infants  
each year**

# Premature Baby Foundation of Taiwan



- January 1992
- Jointly founded by Mackay Memorial Hospital with other non-profit organizations.



individual

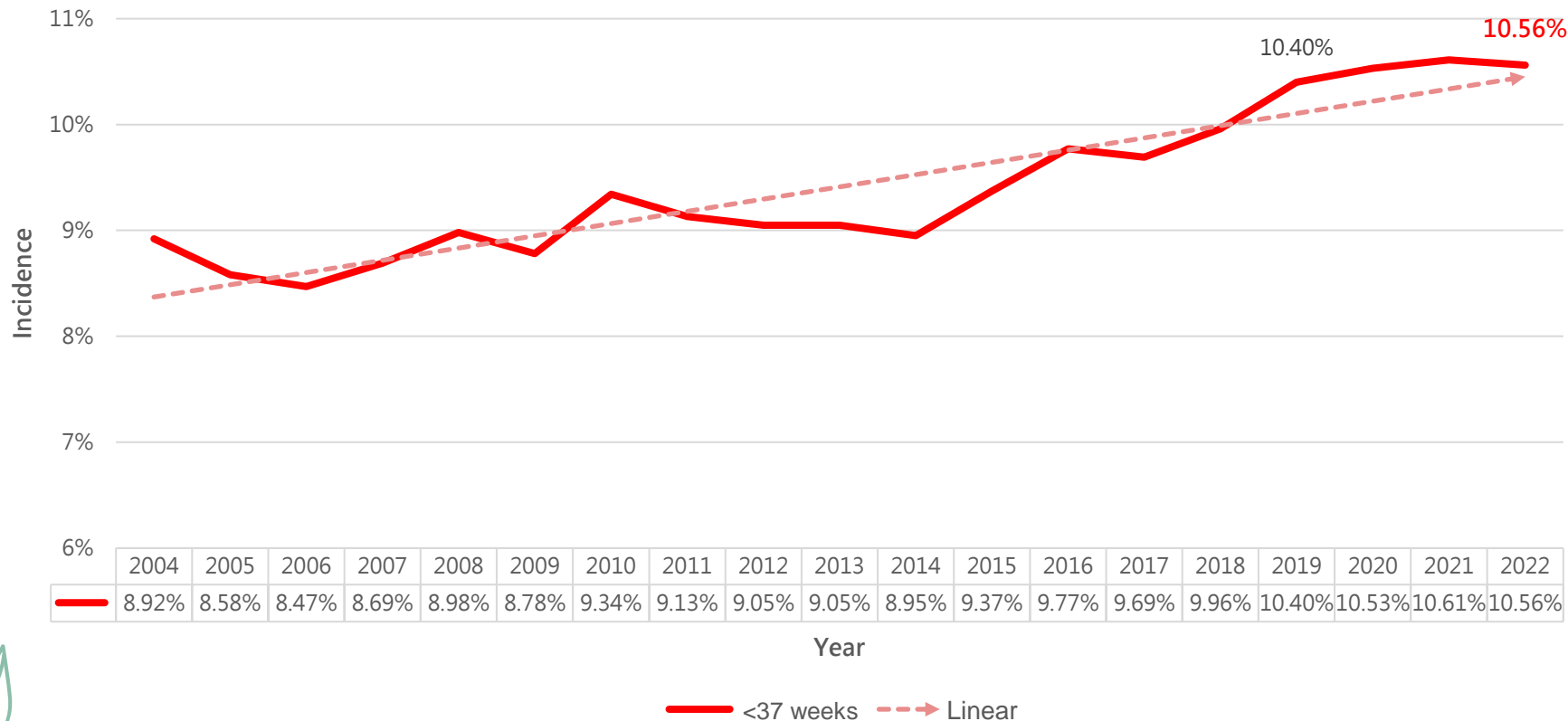


group

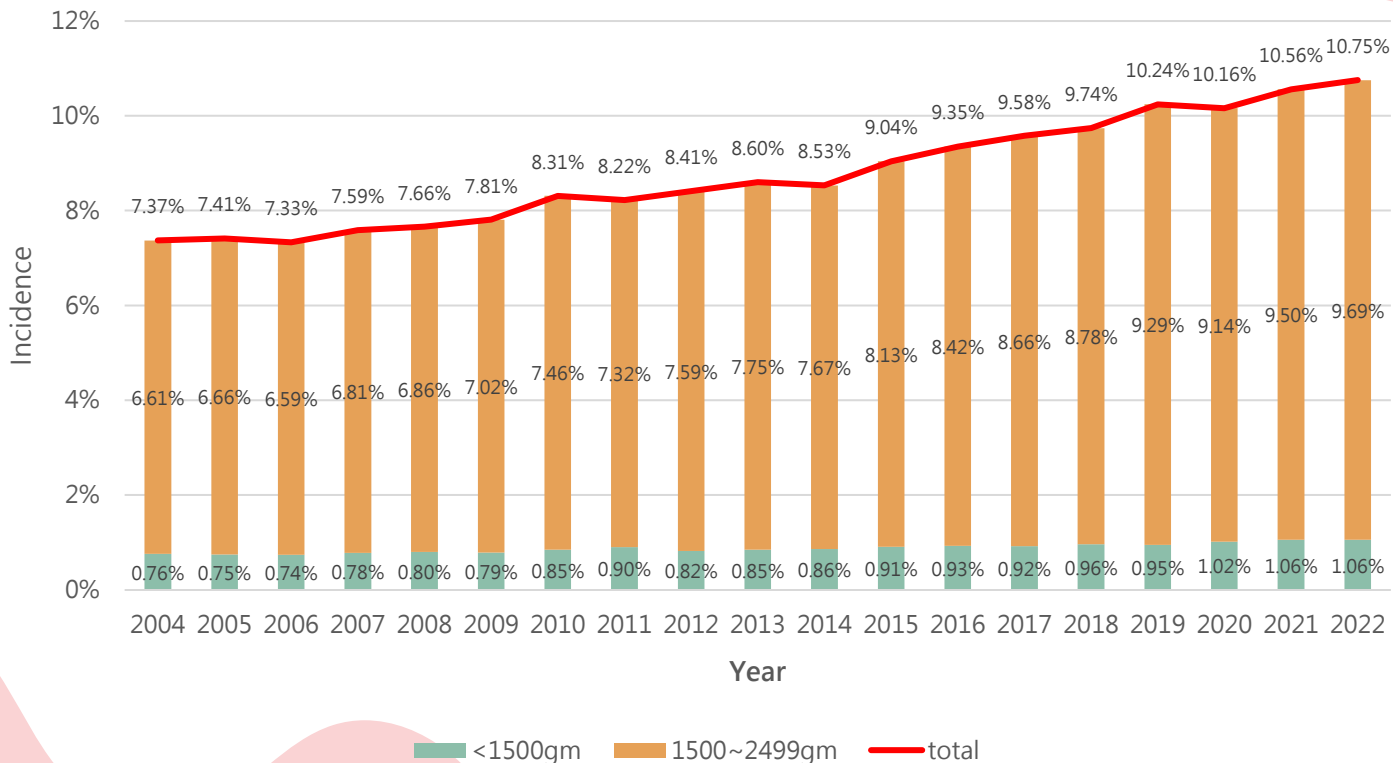


company and  
business entity

# Incidences of Preterm Birth



# Incidences of Low Birth Weight and Very Low Birth Weight



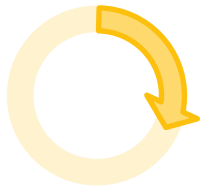
# Prematurity is one of the major causes of neonatal death and long-term morbidity!



The rate of preterm birth has increased from 7.1% in 1998 to a high of **10.75% in 2022**.



One premature baby is born every **30 minutes**.



Over **1200** very low birth weight premature babies born every year. Approximately thirty percent of very low birth weight premature babies are found to have **moderate-severe developmental disabilities**.

# Purposes of Premature Baby Foundation of Taiwan



## Enhancing health care quality

To ensure that every premature infant receives appropriate medical care.



## Committing to prevention of premature births

To ensure correct knowledge and prenatal care are delivered to pregnant women and the publics.



## Building social resonance

To raise government and public awareness of premature birth by all means.



# Important Milestone

1991

● Planning, with the first board meeting

1992~

- Initiated services
- Subsidized premature infant hospitalization expenses
- Conducted health education and promotion related to prematurity
- Organized professional training courses for medical personnel





1995

**National Health Insurance  
was launched in 1995.**



**Better Lives & Well-beings  
of Premies**



Conducting  
follow-up  
examinations  
after discharge.



Provision of rental  
subsidies for home  
medical equipment.

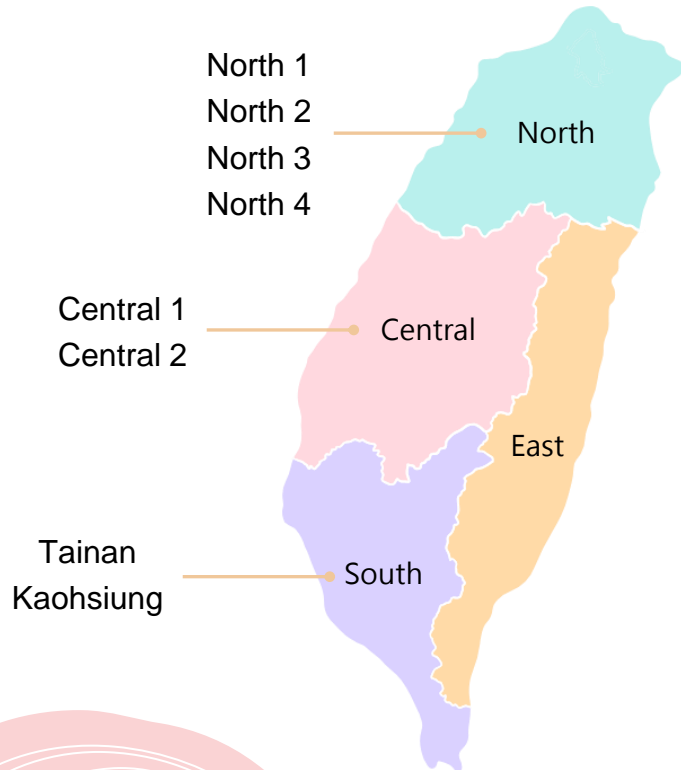


# Members & Enrollment of Taiwan Premature Infants Follow-Up Network (TPFN)



- All VLBW patients admitted to the neonatal intensive care units of the participating hospitals are screened for eligibility.
- Infants **without major congenital malformation and chromosomal abnormality and admitted within 7 days after birth** are recruited to this project.

# Follow-up Team



- The follow-up team in each area consists **of a main investigator, a child psychologist, a case manager (usually a registered nurse)** and sometimes with additional **neonatologists or pediatric neurologists**.
- Data collected at the outpatient database are analyzed regularly.

Zone	Hospital	Neonatologist	Case Manager
North 1	臺大醫院	鄒國英、曹伯年、周弘傑、陳倩儀、顏玳安、黃信中	劉芸秀
	婦幼醫院	方麗容、王培璋、鄭彥辰、吳佳玲	
	國泰醫院	洪依利、沈仲敏、謝武勳	
	永和耕莘醫院	林明弘	
	北醫附醫	蘇一字	
	亞東醫院	梁翔、李佳容、郭子敏、王詩欣	
North 2	新光醫院	穆淑琪、林姪慧、陳怡伶、蔡立儀	黎育伶
	臺北榮總	鄭玫枝、李昱聲、曹珮真、陳威宇、周佳穗	
	台北長庚醫院	翁逸豪、程劭文、林書瑜	
	三軍總醫院	謝國祥	
North 3	台北馬偕醫院	許瓊心、張瑞幸、林佳瑩、張弘洋、陳佳慧、詹偉添	陳淑貞
	新竹馬偕兒童醫院	宋聿翔、劉子瑜、陳政偉、柯信如	林采燕
North 4	林口長庚醫院	林瑞瑩、朱世明、徐任甫、傅仁輝、江明洲、楊長佑、許凱翔、李建忠、賴美吟、吳怡萱	余慕嫻
Central 1	中國附醫	林鴻志、邱曉郁、林湘瑜、蔡明倫、陳映廷、鄭皓文、沈上博	梅麗菁
	中山附醫	陳善銘、李英齊、王杏安	
Central 2	臺中榮總	林明志、王德明、許雅淇、徐仲庭、林怡瑄	陳珮妤
	彰化基督教醫院	蕭建洲、陳曉能、李政翰、陳家玉、陳俐如	
Tainan	成大醫院	黃朝慶、林毓志、杜伊芳、林永傑、陳俐文、余文豪、陳妍如	劉子毓
	奇美醫院	王藍浣、王麟玉、蔡文暉	
	新樓醫院	陳奕吟	
	郭綜合醫院	林愛惜	
	嘉義基督教醫院	黃琳淇、吳宗祐	
Kaohsiung	高雄榮總	王曉萍、張振宗、楊智絜	沈純潔
	高雄長庚	陳志誠、鍾美勇、黃新純、陳豐順、歐陽美珍	
	高醫附設中和醫院	陳秀玲、鍾浩璋、楊書婷、蘇品淳	
	義大醫院	楊詠甯、吳建儀、劉賢冠、吳佩玲	
			楊淑媛

# Expanded Service Program

- 42 hospitals
- For institutions caring preterm infants without sufficient resources
- Provide information and resources relevant to preterm infants follow-up



- Follow-up assessments
- Follow-up clinics at participating hospitals



Parents book appointments



Referral to specialists



# Enrollment & Follow-up



Interviewed and  
Informed

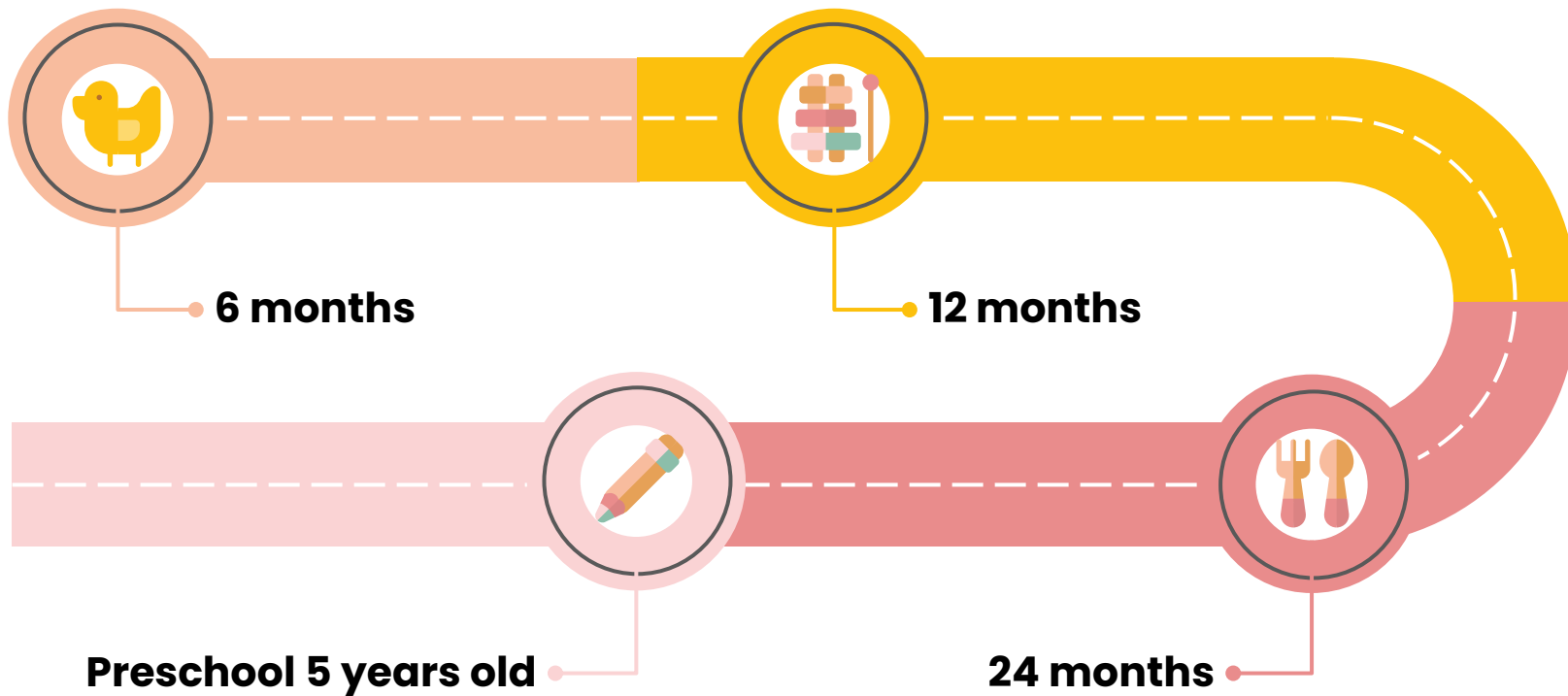


Arrange an  
appointment



Evaluate at  
corrected age of  
6,12,24m and 5y

# Timing of Testing



※ Referral to Early Intervention System if Needed

# Measurements for Growth and Psychomotor Development

## Measurement

Measurements of growth, and assessment of **general health, neurological, and psychomotor development** are performed.



## Psychomotor development

**Under 3 years old:**  
Bayley Scales of Infant Development, 3rd edition (BSID III)  
**5 years old:** Revised Wechsler Preschool and Primary Scale of Intelligence (WPPSI-IV)



## Behavior and Temperament

**Parents and The child's teacher** are asked to fill out an Activity Questionnaire and a Children's Temperament Questionnaire.



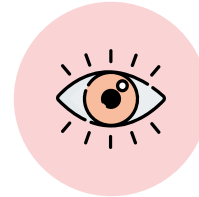


# Neurosensory Examinations



## Hearing test

Hearing test is done **before 4 month-old**. Follow-up evaluation is arranged according to clinical condition.

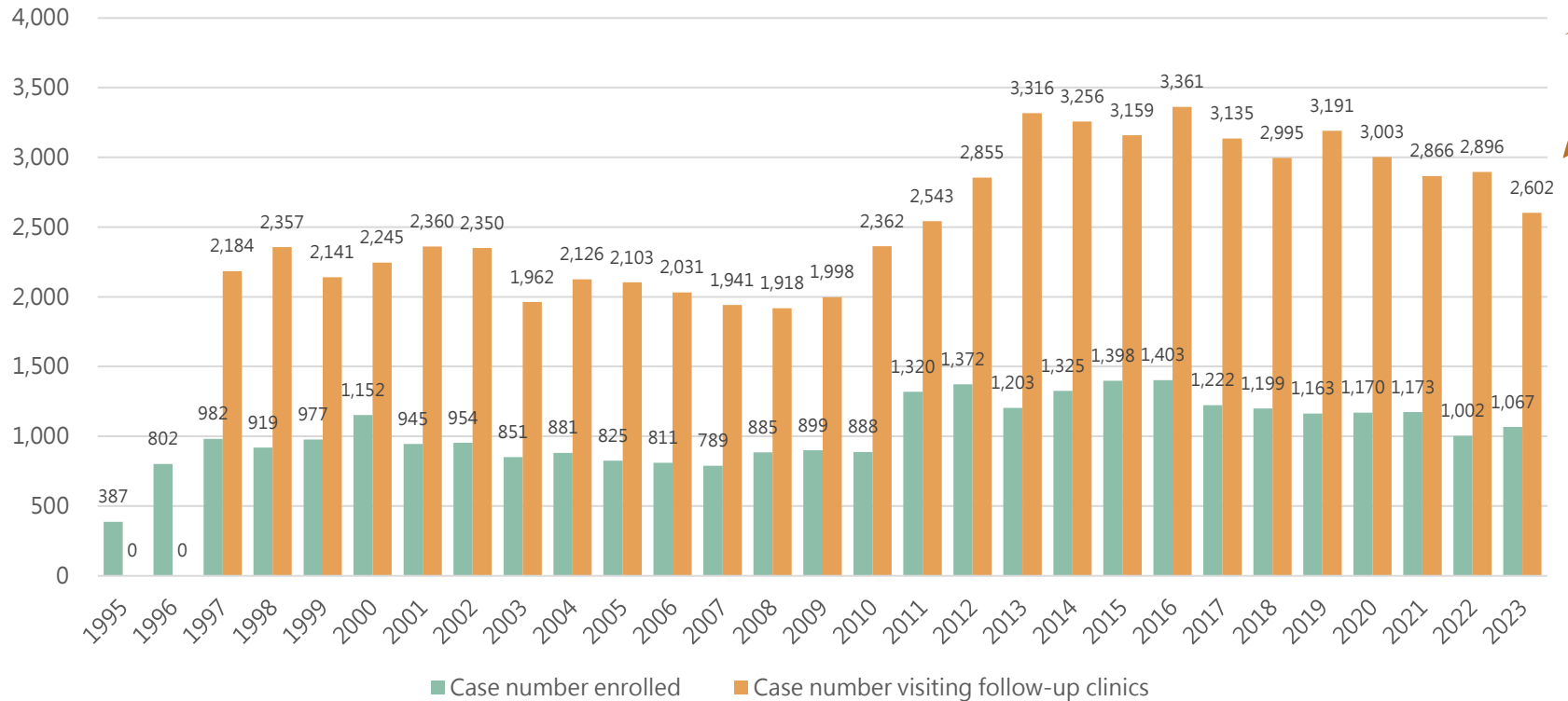


## Eye ground examinations

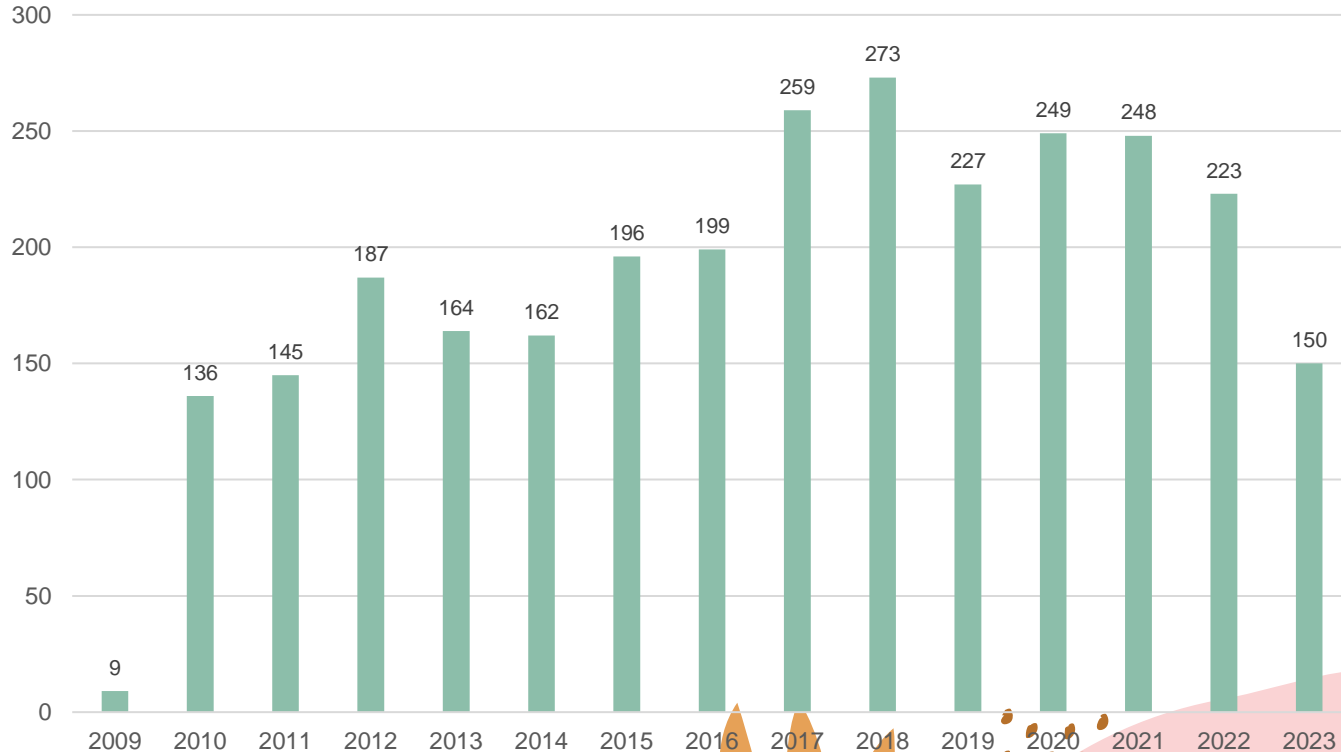
Eye ground examinations are done in **the first year** of life and visual acuity is assessed annually by ophthalmologists.



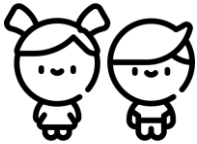
# Case number enrolled each year & case number attended follow-up clinic



# Case number enrolled in expanded service program



# Service volume for premature infants follow-up



**61,786**

**2 years old**

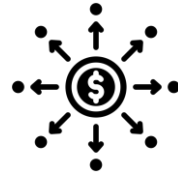
August 1995 -  
September 2021



**3,354**

**5 years old**

2006 - 2020



**NT\$150M**

**Expense**

over 25 years

# Advocating for Premature Infants & Raising Government Awareness

2012

## Meeting with the Health Bureau

Seminar on Discussion of Premature Birth Prevention, Treatment, Follow-up, Home Care, etc.

1117

First **Annual Commemoration of World Prematurity Day** on November 17<sup>th</sup>.



# Advocating for Premature Infants & Raising Government Awareness

2013

## public hearing

Hosted with legislators  
“Speaking up for **Tiny Feet!**” Public Hearing to advocate the medical rights of premature infants.



2018

## public hearing

“Improving the shortage of medicines and medical materials for children”

Taiwan PBF urged the public to establish a logistics platform dedicated to scarce medical resources.



# Government's Actions



Mar. 2017 to Dec. 2017

**Pioneering Program for Follow-up and Care of Very Low Birth Weight Premature Infants.** Commissioned by the Premature Baby Foundation to Execute.

極低出生體重早產兒追蹤  
關懷先驅計畫  
Follow up and care of very low birth  
weight preterm infants-a pilot  
program

成果報告

計畫主持人 張瑞幸醫師  
台灣早產兒基金會

2017/12/01



2019-2022

**The New Taipei City Health Bureau** has been collaborating with the Premature Baby Foundation since 2019 to lead **the Premature Infant Case Management Program.**

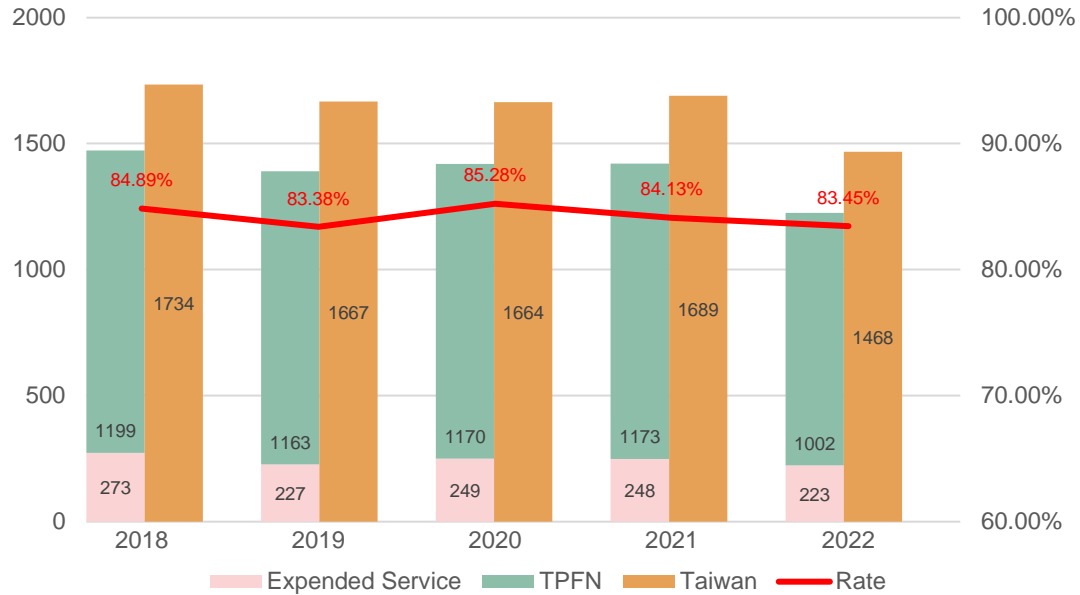


2022-

**Home Care Program for Low (including Very Low) Birth Weight Infants** since 2022. As of October 2023, HPA has collaborated with **80 hospitals**, extending professional care services to home settings.



# VLBW Infants in Taiwan vs TPFN

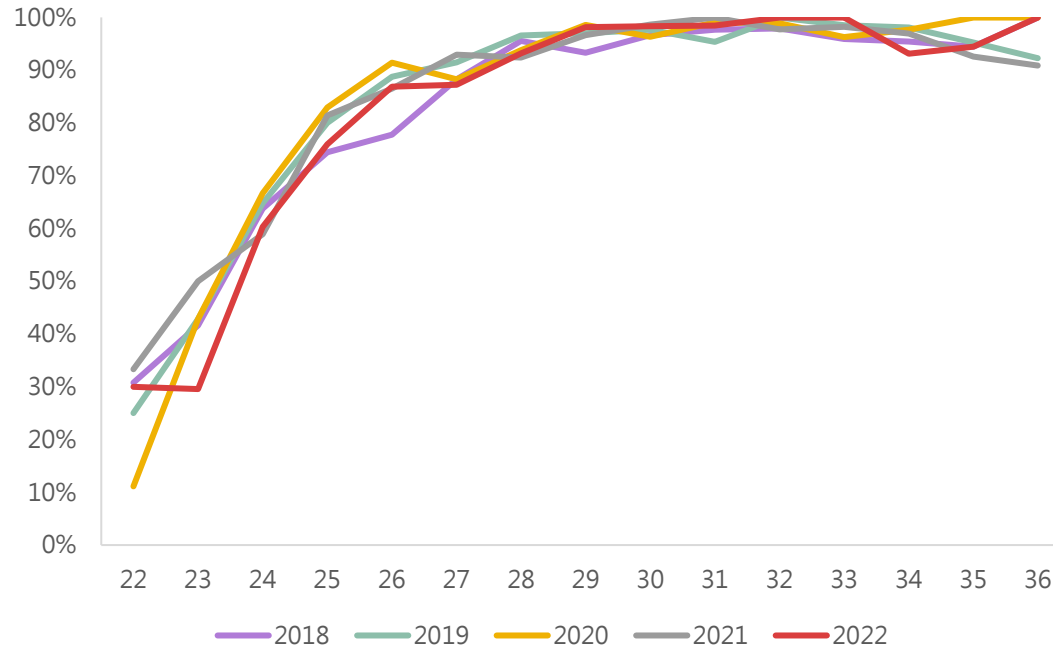




# Survival Rate of VLBW Infants in TPFN, 2022 (By Gestational Age)

GA Year	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	Total
2018	30.8%	41.7%	63.8%	74.4%	77.8%	88.3%	95.5%	93.3%	96.6%	97.7%	97.9%	95.9%	95.5%	94.4%	100.0%	1,197
2019	25.0%	42.9%	64.8%	80.0%	88.8%	91.5%	96.6%	97.0%	97.7%	95.4%	100.0%	98.5%	98.1%	95.2%	92.3%	1,134
2020	11.1%	42.9%	66.7%	82.9%	91.4%	88.3%	93.8%	98.6%	96.4%	99.1%	98.9%	96.3%	97.7%	100.0%	100.0%	1,164
2021	33.3%	50.0%	58.9%	81.4%	86.5%	92.9%	92.4%	96.6%	98.7%	100.0%	97.7%	98.2%	97.0%	92.6%	90.9%	1,151
2022	30.0%	29.5%	60.3%	75.9%	86.9%	87.3%	93.2%	98.1%	98.4%	98.5%	100.0%	100.0%	93.1%	94.4%	100.0%	989

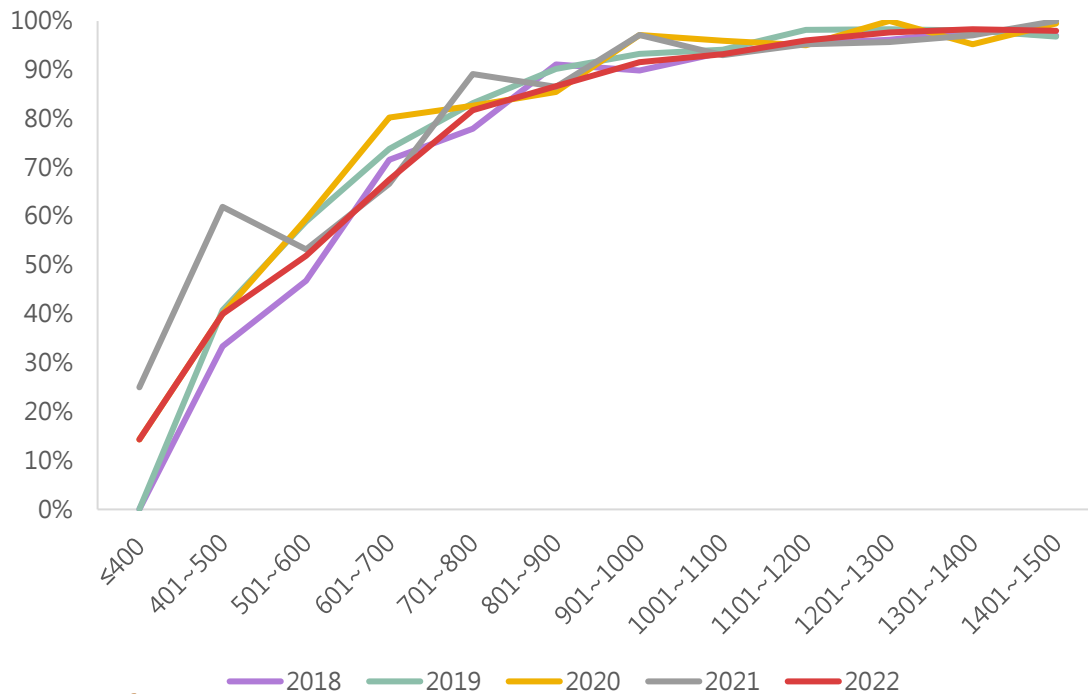
# Survival Rate of VLBW Infants in TPFN, 2022 (By Gestational Age)



# Survival Rate of VLBW Infants in TPFN, 2022 (By Birth Weight)

BW Year	≤400	401~500	501~600	601~700	701~800	801~900	901~1000	1001~1100	1101~1200	1201~1300	1301~1400	1401~1500
2018	0.0%	33.3%	46.8%	71.6%	77.9%	91.1%	89.8%	93.6%	95.3%	96.1%	98.0%	97.0%
2019	0.0%	40.7%	58.9%	73.8%	83.1%	90.2%	93.3%	94.1%	98.2%	98.3%	98.0%	96.8%
2020	14.3%	40.0%	59.5%	80.2%	82.6%	85.4%	97.1%	96.0%	95.0%	100.0%	95.2%	99.5%
2021	25.0%	61.9%	53.2%	66.7%	89.2%	86.5%	97.1%	93.0%	95.2%	95.7%	97.1%	100.0%
2022	14.3%	40.0%	51.9%	67.5%	81.7%	86.7%	91.6%	93.2%	96.0%	97.7%	98.3%	98.0%

# Survival Rate of VLBW Infants in TPFN, 2022 (By Birth Weight)



# Survival rate and follow-up rate in TPFN

Year	Enrolled	Survive to discharge	Survival rate	Death after discharge	Survive at 2 years of age	Follow up rate of survivors at 2 years of age	Rate of complete BSID III data
2016	1,397	1,247	89.3%	6	1,241	1,020 (82.2%)	995 (97.5%)
2017	1,217	1,081	88.8%	12	1,069	905 (84.7%)	879 (97.1%)
2018	1,197	1,052	87.9%	6	1,046	905 (86.5%)	863 (95.4%)
2019	1,155	1,036	89.7%	10	1,026	868 (84.6%)	845 (97.4%)
2020	1,164	1,059	91.0%	7	1,052	861 (81.8%)	842 (97.8%)
Total	6,130	5,475	89.3%	41	5,434	4,559 (83.9%)	4,424 (97.0%)

# Morbidities of Very Low Birth Weight Preterm Infants

Morbidty/Period	Period I 1998~2007	Period II 2008~2017	P value
	n=8,807	n=11,649	
Sepsis/Meningitis	117(15.83%)	2060 (18.24%)	0.100
Necrotizing enterocolitis	695 (8.06%)	634 (5.45%)	<0.001
Retinopathy of prematurity (ROP)	3308 (48.37%)	4223 (41.49%)	<0.001
Severe ROP (3+4+5)	780 (11.44%)	1076 (10.57%)	<0.001
Intraventricular hemorrhage (IVH)	2749 (44.47%)	4843 (43.12%)	0.087
Severe IVH (3+4)	702 (11.36%)	962 (8.57%)	<0.001
Cystic periventricular leukomalacia	346(5.8%)	466 (4.17%)	<0.001
Post-hemorrhagic hydrocephalus	174(3.6%)	422 (3.87%)	0.402

# Definition of NDI

Mild or no neurodevelopmental impairment (NDI)

A Bayley-III **cognitive** composite score of **85 or higher**

A Bayley-III **motor** composite score of **85 or higher**

GMFCS level **0 or 1**

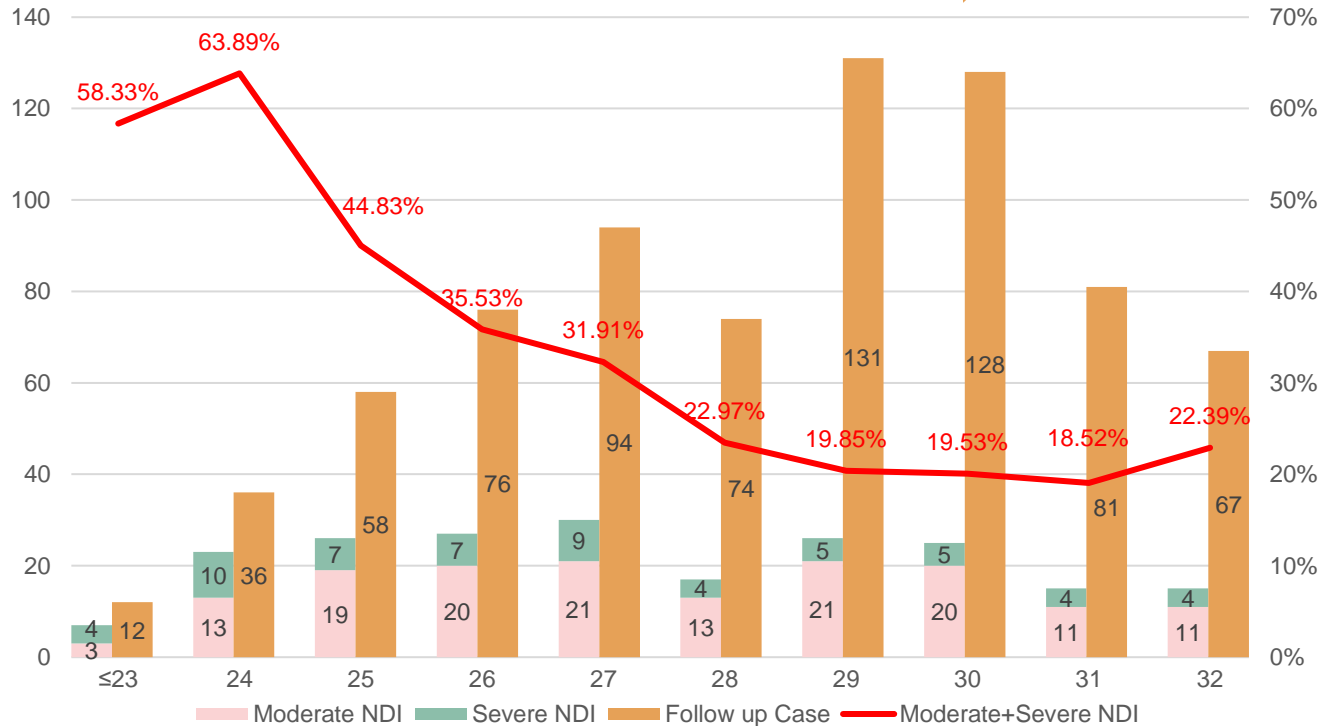
Moderate NDI

A Bayley-III **cognitive** composite score **or motor** composite score of **70 to 84** or GMFCS level **2 or 3**.

Severe NDI

A Bayley-III **cognitive** composite score or **motor** composite score **lower than 70**, GMFCS level **4 or 5**, bilateral blindness, or bilateral severe functional hearing impairment

# NDI of Infants Enrolled in 2020





# Out-Patient Medical Resources Usage at 2 Years of Age in VLBW Infants born in 2011-2017

Outpatient treatment	Patients
	n/N (%)
<b>Sensation (Hearing and vision)</b>	270/6080 (4.4)
<b>Rehabilitation (PT, OT, ST and unspecified rehabilitation therapy)</b>	2095/6080 (34.5)
PT	735/6080 (12.1)
OT	544/6080 (8.9)
ST	1010/6080 (16.6)
<b>Unspecified rehabilitation therapy</b>	1045/6080 (17.2)
<b>Early intervention service</b>	1001/6080 (16.5)
<b>Neurology</b>	248/6080 (4.1)
<b>Child psychiatry</b>	153/6080 (2.5)
<b>Other</b>	740/6080 (12.2)
<b>Total</b>	2645/6080 (43.5)

# Recent Publications

- Lan-Wan Wang, Chi-Hsiang Chu, Yung-Chieh Lin, and Chao-Ching Huang, for Taiwan Premature Infant Follow-Up Network. **Trends in Gestational Age-Related Intelligence Outcomes of School-Age Children Born Very Preterm from 2001 to 2015 in Taiwan.** J Pediatr 2023;261:113584.
- Ming-Chou Chiang, Yen-Ting Chen, Eugene Yu-Chuan Kang, Kuan-Jen Chen, Nan-Kai Wang, Laura Liu, Yen-Po Chen, Yih-Shiou Hwang, Chi-Chun Lai, and We-Chi Wu. **Neurodevelopmental Outcomes for Retinopathy of Prematurity: A Taiwan Premature Infant Follow-up Network Database Study.** Am J Ophthalmol 2023 Mar:247:170-180.
- Chia-Ling Wu, Chia-Huei Chen, Jui-Hsing Chang, Chun-Chih Peng, Chyong-Hsin Hsu, Chia-Ying Lin, Wai-Tim Jim, Hung-Yang Chang on behalf of the Taiwan Premature Infant Follow-up Network. **The effect of patient volume on mortality and morbidity of extremely low birth weight infants in Taiwan.** Journal of the Formosan Medical Association 122 (2023): 1199-1207.
- Wang LW, Lin YK, Lin YC, Huang CC; Taiwan Premature Infant Follow-up Network. **Early Mental Trajectories Predict Different Cognitive Levels at School Age in Very Preterm Children.** Neonatology. 2022;119(2):222-229.

# Future Outlook

01



**Advocate and  
Seek  
Cooperation**

02



**Expand the  
Services**

03



**Enhance  
the Quality**

04



**Promote Our  
Beliefs &  
Achievements**





**THANK YOU ALL  
for your care and love  
for premature infants.**