小胖威利罕见病关爱中心

PWS

Prader- Willi Syndrome Care&support Center

不止肥胖这么简单!

Speech at the International Conference on June 25, 2025

关注小胖威利 点亮希望之光

Focus on Prader-Willi Syndrome, Light Up the Beacon of Hope

林晓静

中国遗传学会会员
浙江小胖威利罕见病关爱中心理事长
浙江省罕见病分会儿童罕见病学组顾问
中国残疾人康复协会罕见病康复专委会委员

Member of the Genetics Society of China
Chairman of Zhejiang Prader-Willi Rare Disease Care Center
Consultant of the Pediatric Rare Disease Group of Zhejiang Province Rare Disease Branch
Member of the Rare Disease Rehabilitation Committee of the China Association for Disability Rehabilitation

我是中国普拉德威利组织的创始人林晓静，非常荣幸有机会在这里，向大家介绍我们中国PWS的故事.

I am Lin Xiaojing, the founder of the China Prader-Willi Organization. It is a great honor to be here to share with you the story of PWS (Prader-Willi Syndrome) in China.

PWS

我的女儿11岁才确诊为PWS，为了让更多的像我女儿一样的其他病友少走就医的弯路，早日得到有效治疗，于2017年注册成立了服务全中国普拉德威利综合征患者及其家属的非营利组织，我们始终围绕着以下四个方面做病友服务：

My daughter wasn’t diagnosed with PWS until she was 11 years old. To help others like her avoid the detours in the medical journey and receive effective treatment sooner, I established a nonprofit organization in 2017 serving PWS patients and their families across China. Our work focuses on four main areas:

一、开展小胖威利疾病知识科普宣传。

1. Promoting Public Awareness and Medical Education of PWS

降低小胖威利疾病的误诊率、漏诊率,真正做到早诊断早干预早治疗，提高患儿的预后水平。

To reduce misdiagnosis and missed diagnosis, we promote early detection, early intervention, and early treatment to improve outcomes for patients.

在51个城市的医学会场开展280多场宣传活动,发放15万余份普拉德威利综合征疾病知识介绍手册;在50多场大型医学会议做《你不了解的普拉德威利》主题演讲;邀请专家举办了50多场网络直播，最大的播放量超50万。

We have held over 280 educational events in 51 cities, distributing over 150,000 PWS information brochures. I have given more than 50 keynote talks at major medical conferences under the theme “The Prader-Willi Syndrome You Don’t Know.” And held over 50 expert-led online webinars, with the highest viewership exceeding 500,000.

PWS

联合百余家医院发起每年的11月15日为中国的“小胖威利关爱日”；联合中国5家著名医院举办7场提升基层医生诊疗普拉德威利能力培训会议；

Collaborated with over 100 hospitals to designate November 15 as “China Prader-Willi Care Day.” Co-hosted 7 training sessions with 5 leading Chinese hospitals to improve diagnostic capabilities among grassroots physicians.

联合专业视频制作公司制作了13个微电影，其中《星空漫游者》播放量超千万，获得多个奖项，还获得200万元传播奖励金。我们自己制作了700个短视频来传播，播放量最高的有400多万。联合知名媒体平台拍摄制作的《儿子饿得吃狗粮，我却不给吃饭》播放量超千万，评论区的留言点赞都超过1万。

Produced 13 short films with professional studios — the film “Stargazer” has been viewed over 10 million times and won several awards, including a ¥2 million broadcast grant. Independently produced 700+ short videos — the most popular reaching over 4 million views. A documentary titled “My Son Was So Hungry He Ate Dog Food, but I Still Couldn't Feed Him” was viewed over 10 million times, with over 10,000 likes and comments.

PWS

@李娃娃
他们看起来好像很“富足”但其... 展开
2023-09-19 21:58 · 发布于新疆

永远吃不饱是种怎样的体验 #街角人生 #人间真实在快手
播放量：1,278.8万
点赞量：35.7万
快手

他们看起来好像很“富足”但其实，上天已经剥夺了他...
播放量：730万
点赞量：26.8万
快手

去年我记录了一群特殊的“小胖”他们一生都在减肥#小...
播放量：512.1万
点赞量：18.9万
快手

通过努力，据不完全统计，500多家媒体报道普拉德威利综合征，其中国家级媒体就19次报道普拉德威利综合征。

Through our efforts, over 500 media outlets have reported on PWS, including 19 features in national-level media.

"小胖"，早点见！

2022-02-28 21:32:59
来源：新华社

浏览量106.8万

新华视频 查看详情 >

利综合征是一种人群发病率仅约

天性

诊疗微指南 | 小胖威利误诊率
m.peopledailyhealth.com

人民日报健康客户端 权威医生在身边

人民日报健康客户端·罕见病频道

诊疗微指南 第1期

小胖威利关爱日： 每年的11月15日是小胖威利关爱日。小胖威利综合征，又名普拉德-威利综合征，是一种罕见的多系统异常的遗传病，已被纳入国家《第一批罕见病目录》。目前，国内患者预计**超过十万人**，误诊率**高达95%**。本期诊疗微指南聚焦小胖威利患者的诊疗、干预和社会保障，邀请权威专家做科学解读。

罗小平
华中科技大学同济医学院
附属同济医院儿科学系主任

出诊时间：
周一下午、周四下午(光谷院区)
周二下午、周五上午(汉口院区)

诊断

小胖患者早期肌张力低下、喂食困难，后期摄食旺盛的症状，常常被家长和医生所忽略。若发现孩子有疑似症状，可以借助甲基化表观遗传检测、甲基化PCR或MLPA检测，确诊后尽早治疗。

拯救

中国新闻网，梳理天下新闻

如何拯救被"食欲"撑坏的孩子？百位专家齐聚蓉城开启"头脑风…
更多权威资讯，尽在新华社客户端

如何拯救被"食欲"撑坏的孩子？百位专家齐聚蓉城开启"头脑风…
人民号——汇聚人民的力量

从二个数据可以分析我们科普宣传的重要意义的显现：一是确诊年龄从之前的七八岁、十多岁甚至二十多岁才确诊，到如今的最早出生7天就确诊的；二是这几年确诊人数呈爆发式增长，是之前的十倍二十倍以上。同时也让更多医生知道了解什么是普拉德威利综合征。

As a result of our hard work, the diagnosis age has shifted from 7–20+ years to as early as 7 days after birth. Confirmed case numbers have grown explosively — increasing more than 10–20 times in recent years. Awareness among medical professionals has significantly improved.。

二、积极有序开展政策倡导工作

2.Advocating for Policy Support

倡导小胖威利治疗药物纳入医保的特殊门诊病种目录，从经济支出根本上减轻病友的负担，缓解家庭经济压力；倡导残联对患儿及家庭给予救助等

To reduce the financial burden on families, we have advocated for PWS treatments to be covered by public insurance and called for social assistance from government disability agencies.

PWS

直接推动国内地方首个普拉德威利综合征患者资助基金项目“爱有威力”落地；

We initiated China’s first local PWS patient aid fund, “Love Has Power.” (Power sounds like Willi in Mandarin)


安徽省医疗保障局文件

皖医保秘〔2021〕36号

安徽省医疗保障局关于印发《安徽省基本医疗保险门诊慢特病病种目录（试行）》的通知

各市医疗保障局，局各处室、单位：

为进一步规范基本医疗保险门诊慢性病、特殊病（以下简称门诊慢特病）管理政策，按照《安徽省基本医疗保险门诊慢性病、特殊病管理办法（试行）》（皖医保秘〔2020〕132号）要求，

推动多个省市将PWS治疗纳入医保，减轻了患者家庭的经济负担。

Promoted PWS treatment coverage in public insurance systems in multiple provinces.

推动了中国红十字基金会成长天使基金“小胖威利患者关爱项目定点诊疗中心”在270多家医院落地，2周岁以内的小胖威利患者可以免费注射生长激素6个月，可申请2次。Facilitated the launch of the “PWS Patient Care Program” under the China Red Cross Foundation in over 270 hospitals. Children under age 2 can receive two free rounds of 6-month growth hormone injections.

推动了中国普拉德威利诊疗联盟和中华医学会PWS协作组的成立。Promoted the establishment of the China PWS Clinical Alliance and the Chinese Medical Association PWS Working Group.

三、 开展医疗合作活动，加强国际交流，学习和分享国内外最新治疗资讯

3.Medical Collaboration and International Exchange

To share the latest treatment strategies and overcome access barriers

PWS

针对PWS患者并发症多看病难的问题，联合二十一家医院举办了69场多学科义诊暨医患交流活动,直接惠及1735个患者家庭；针对看病挂号难的问题，开通了146家医院的180多位爱心医生的就诊绿色通道，优先PWS患者的诊疗

Partnered with 21 hospitals to hold 69 multidisciplinary consultation and patient–doctor exchange events, directly benefiting 1,735 families. To address the difficulty of getting medical appointments, we created a priority care program with 180+ compassionate doctors across 146 hospitals.

建立12个专家网络咨询群,足不出户即可咨询病情，可以免费得到专业的诊疗指导；为了有效缓解照护者的心理压力，邀请专家举办了19场“打破那道心墙”心理疏导活动，让323个家庭得到了帮助。

Established 12 expert-led online consultation groups for remote and free medical advice.

Held 19 mental health workshops titled “Breaking Down the Wall of the Mind” to support 323 families under stress.

举办了35场社会融入活动，邀请了383个普拉德威利患者及其家属参加。直接推动多个药物进入临床适应症试验及基因药物研究。

Hosted 35 social integration events for 383 PWS patients and their families.

Supported clinical trials and genetic research on multiple PWS-related drugs.

四、建立小胖家园

为小胖患儿提供了一个没有食物诱惑的环境，通过科学的饮食方法和有效的运动，先后入住的86个小胖孩子都成功减重,健康状况不同程度的改善。

4.Creating the “Xiaopang Home” – A Safe Residential Program；、

We founded a special residential center for children with PWS that eliminates food temptations and provides structured diet and exercise programs. All 86 residents have lost weight and improved their health in various levels since moving in.

效果最好的是一位来自上海的17岁小胖，12个月时间从227斤减到120斤，减轻了107斤，而且更加神奇的是身体各项指标完全正常，来之前空腹血糖高到16mmol/L以上，每天需要注射治疗糖尿病的药物。来之后，一个月时间血糖就在正常范围之内，第二月就停止了注射药物，血糖仍然维持在正常的范围之内，连久治不愈的糖尿病足也自然痊愈了。

One standout case: A 17-year-old patient from Shanghai lost 118 lbs (from 250 lbs to 132 lbs) in 12 months. Prior to admission, his fasting blood sugar level exceeded 16 mmol/L, his blood sugar normalized within a month after arrival, diabetes injections stopped in the second month, blood sugar stayed in normal range and his chronic diabetic foot healed completely.

获奖情况：
Awards and Recognition:

荣誉证书

浙江小胖威利罕见病关爱中心：

恭喜贵组织在2022年度优秀罕见病患者组织评选活动中，荣获：

最佳传播—闻名遐迩奖

特发此证，以资鼓励！

蔻德罕见病中心
中国罕见病组织发展网络
2023年4月9日

凝心聚益
《中国慈善家》
2024年度慈善盛典

年度优秀项目
拯救贪吃的天使

《中国慈善家》杂志社
2025年1月

The organization has won multiple national honors, including awards from Tencent, Xinhua Net and China Philanthropist Magazine, for its outstanding advocacy, public education and patient support in Prader-Willi Syndrome.

因为在普瑞德-威利综合征方面的杰出倡导、公众教育和患者支持，获得了多项国家级荣誉，包括腾讯、新华网和《中国慈善家》杂志的奖项。还连续四年被基金会评为优秀合作伙伴/机构。

我们的使命：人人皆知小胖威利，建立小胖家园，为小胖群体建立平等、受尊敬的社会环境。
核心文化：每一位小胖威利人都有其存在的意义和价值，都值得被爱照亮。

Our Mission: To make Prader-Willi Syndrome known to all, to create a safe home for those affected, and to build a respectful and inclusive environment for the PWS community.Our Core Belief: Every person with PWS has unique value and deserves to be loved and seen.

以上即是PWS在中国的故事和我们的努力， 我很感激有这个机会代表中国PWS家庭来美国参加这次大会，一起交流分享，学习经验 。

This is the story of PWS in China and the efforts we’ ve made so far. I’ m truly grateful for the opportunity to represent Chinese PWS families here in the U.S., to participate in this conference, exchange ideas, and learn from one another.

最后，祝本次大会圆满成功，也祝大家身体健康！再次感谢大家。

In closing, I wish this conference great success and good health to everyone here. Thank you again!

小胖威利罕见病关爱中心

PWS

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不止肥胖这么简单!