

# 瓷娃娃罕见病关爱中心简介

## China-Dolls Center for Rare Disorders (CCRD)

瓷娃娃罕见病关爱中心（以下简称中心），前身为瓷娃娃关怀协会，成立于2008年5月，由成骨不全症等罕见病患者发起，并于2011年在北京市民政局注册。2015年注册成立济南瓷娃娃罕见病关爱中心。目前有北京和山东济南两个办公室。中心是一个从事公益性、非营利性社会工作的民间公益组织，致力于成骨不全症患者开展医疗推动、医疗救助、社群互动、政策倡导、公众参与等工作，促进社会和公众对于成骨不全症人士的了解和尊重，消除社会对该群体的歧视，维护该群体在医疗、教育、就业等方面的平等权益，推动有利于成骨不全症群体的社会保障相关政策出台。成立至今，中心筹集善款总额3000多万元，提供医疗康复救助1600余人次，服务覆盖3000多个各类罕见病、残障家庭。

**核心价值观：**独立自主，平等尊重，多元共融。

**核 心 文 化：**每一个生命都有其存在的意义，  
每一个生命都应该被尊重。

**愿 景 使 命：**携手成骨不全症患者和家庭，通过社群互助、联动多方参与，提升社群意识和公众认知；推动医疗研究、普及综合治疗、完善医保和教育政策。营造平等、共融的无障碍社会环境。

**口 号：**还好，我们的爱不脆弱。

China-Dolls Center for Rare Disorders (CCRD), formerly known as China-Dolls Care and Support Association, was founded by individuals with Osteogenesis imperfecta (OI) and various rare disorders in May of 2008. CCRD was registered under Beijing Civil Affairs Bureau in 2011. The Jinan China-Dolls Center for Rare Disorders was founded and registered in 2015. Currently, CCRD has offices in Beijing and Jinan, Shandong Province.

As a non-profit and non-government organization, CCRD works with and for people with OI on local medical promotion, medical aid, peer mutual support by empowerment, policy advocacy and public engagement. We aim to raise public awareness of OI, to eliminate discriminations and prejudices, to secure equal rights of people with OI on healthcare, education employment and other areas, and to promote related policies to benefit people with OI.

CCRD has raised more than 30 million RMB since established. We have provided medical aid and rehabilitation services to more than 1600 man-time. The services of CCRD cover more than 3000 families of people with disabilities or different rare diseases.

**Our Core Values:** Independence, Equality and Respect, Diversity and Integration.

**Our Core Culture:** Every life serves its purpose, every life shall be respected.

**Our Vision & Mission:** We work together with and for people with OI and their families, through peer supports, multi-actors engagement, OI community awareness raising, public education, medical research, multidisciplinary treatment promotion, health and education policy advocacy. To create an equal, inclusive and barrier-free society.

**Our Slogan:** Love is still strong.

## 成骨不全症

### Osteogenesis Imperfecta (缩写为 OI)

成骨不全症/脆骨病，是一种具有临床异质性的遗传性结缔组织病，可以视为从幼年时期开始的骨质疏松，患者有一个美丽的名字：“瓷娃娃”。

成骨不全症以骨质脆弱、易骨折为主要症状，也常伴有如下症状：肌肉力量弱、牙齿发育不全、蓝巩膜、脊柱侧弯、听力受损等。成骨不全症是由胶原蛋白基因或其相关基因突变导致。当这些基因作用异常时，就对胶原蛋白的生成产生不同程度影响，而胶原蛋白是保持骨骼强健的重要成分。

成骨不全症具有高度可变性，轻型无畸形、正常身高、很少骨折。重度患者可能经历上百次骨折，甚至在胎儿期发生死亡。

成骨不全症发病率为一万五千分之一到两万分之一，在男性和女性，以及不同的种族和民族中的发病率相同。按照人口比例计算，中国的患者约有十万人以上。

成骨不全症目前在全球范围内尚不能治愈，但可以通过多学科治疗和康复锻炼尽可能改善患者的身体情况。治疗通常包括药物治疗（双磷酸盐类等）、物理训练、辅具/支具配合、手术治疗（髓内钉内固定手术）、日常锻炼、水疗、脊柱侧弯预防。

成骨不全症有遗传风险，已有患者的家庭或成年患者在计划生育下一代时，可及时进行夫妻、子女的基因检测和胎儿孕检，降低下一代患病风险，生育健康宝宝。

Osteogenesis Imperfecta (OI), or "brittle bone disease", is a clinically heterogeneous heritable connective tissue disorder. It could be regarded as osteoporosis starting from childhood to some degree. "China-Doll" is another beautiful name for OI patients.

The clinical features of OI commonly include bone fragility and easy susceptibility to fracture, bone deformity, growth deficiency, other signs sometimes occur like muscle weakness, dentinogenesis imperfecta, blue sclera, scoliosis and deafness. OI is caused by mutations of the collagen gene or associated genes. Collagen plays an important role in keeping bone strong. When these genes act abnormally, they affect the collagen production in varying degrees.

OI has many phenotypes ranging from subclinical to lethal. The mild type may lead to free deformity, normal height, and rarely fracture. Severe patients may experience hundreds of fractures, or even die during fetus period.

OI affects about one in 15,000 – 20,000 people regardless of gender and race. It means there are approximately one hundred thousand people with OI in China.

For now, Osteogenesis Imperfecta (OI) still cannot be cured. But patients' physical condition could be improved mostly by multidisciplinary treatments and rehabilitation. Medical treatments usually include drug therapy (such as bisphosphonates), physiotherapy, auxiliary devices or braces, surgical treatment (intramedullary nail fixation), daily exercise, hydrotherapy and scoliosis prevention.

Because of the genetic risk of OI, when families have members with OI or people with OI plan to give birth to next generation, a genetic test and pregnancy test can reduce the risk of having OI to ensure the health of a baby.

## 多学科综合治疗推动

### Multidisciplinary treatment Promotion



我们致力于推动各地方基层医院正确诊断成骨不全症，从患者的角度出发，以回归社会为目标，有正确治疗概念，进行正确转诊，并发展相关治疗；推动已经进行药物和手术治疗、并有一定病友基础的三甲医院形成成骨不全症多学科综合治疗体系；推动相关医学研究开展；收集基础数据，促进医保相关政策完善。联合药企、医院推动成骨不全症药物适应症工作，让患者有药可用。最终实现患者可在承受的经济范围内就可以就近、持续、全面治疗的医疗环境。

We facilitate the accurate diagnosis of OI in hospitals at local level. We suggest that treatments should include patients' perspectives and being social-integration oriented. We facilitate accurate transferal treatment and develop relevant treatment with correct concept. We also promote developing multidisciplinary treatment system in 3A hospitals which have already launched relevant medication, surgery and rehabilitation. Besides, we promote the development of medical research on OI and the improvement of medical insurance policies for people with OI through baseline data collection. In addition, the program cooperates with hospitals, pharmaceutical companies and other partners to promote OI drug indications studies so that the patients will have access to certain medicine nationwide. Together with all relevant parties, we could develop a medical environment where people with OI could get the nearest, comprehensive, timely and efficient medical treatment within their affordable economic limit.

#### 代表项目 THEME PROJECT

##### “康复马拉松”医疗巡诊

##### “Rehabilitation Marathon” Medical rounds

中心联合国内外知名专家，包括内分泌、骨科、康复、遗传等组成专家团队，每年联合全国3-4个省市医院共同举办康复巡诊活动，通过医生培训、实操演示、多学科诊疗、建立医生交流网络等方式，提升各地区医院医生对成骨不全症治疗的水平、促进综合治疗，为当地患者制定全面、系统的治疗及全人康复方案，最终形成就近就医、全面就医、及时高效就医的医疗环境。项目于2012年启动，截至2017年初，已走过11个城市，进行了13次巡诊，开设数场医疗讲座，累计服务病友350多人，培训医务工作者200余人。

CCRD works alongside domestic and international experts including endocrine, orthopedics, rehabilitation and genetics to hold medical rounds in 3-4 provincial hospitals every year. Through doctors training, practical demonstrations, multidisciplinary treatment and doctors network establishment, the project improves the medical level of local doctors, promotes comprehensive treatment. The local patients will acquire a systematic medical treatment plan and get essential assistive devices. The ultimate goal is to develop a medical environment where people with OI could get accessible, comprehensive, timely and efficient medical treatment. Since it launched in 2012, the project has gone through 11 cities, 13 rounds and set up numbers of medical lectures. There have been more than 350 OI patients served and more than 200 medical workers trained.



## 医疗救助

### Medical Aid Service

为了满足成骨不全症病友个性化、长期、多学科综合的医疗需求，中心通过医疗救助工作，帮助最有需要的病友，使他们的身体能够及时、正确地获得医疗康复改善。

In order to meet personalized, long-term, and multi-disciplinary medical needs of OI patients, CCRD provides medical aid services to people with OI, particularly those most in need. CCRD ensures them in time and appropriate medical treatment.

#### 代表项目 THEME PROJECT

##### 钢铁侠计划 Iron Men Plan



从康复、药物和手术等方面来综合支持病友进行及时、正确的治疗，提倡“全人康复”的理念，预防为先。项目同时监督医疗行为，为病友进行综合评估，根据自身的状况，制定多学科介入的合理健康管理方案，通过科学的康复锻炼，增强自身的肌肉力量，通过早期预防，降低肢体发生骨折、变形的风险，享有好的生活质量，拥有正常的朋友圈和生活圈，顺利融入社会生活，变身“钢铁侠”！

The project provides financial aid to help people with OI to access in time and appropriate medical treatment including rehabilitation, medicine and operation. We advocate holistic approach, preventive and multidisciplinary treatment in this project. The project not only monitors medical behavior of patients, but also conducts comprehensive medical evaluation for them to develop a customized health management plan with multidisciplinary intervention, so that they can strengthen their muscles through scientific rehabilitation and reduce the risk of bone fracture and deformity through early prevention. Therefore, people with OI can also enjoy a good quality of life with their own social network and better integrate into social life as an "iron man"!

申请“钢铁侠计划”项目请扫描二维码  
Apply for Iron Men Plan, please scan QR code



##### 爱流转计划

##### Pay it Forward Emergency Loan Scheme



“爱流转公益借款联盟”2015年在浙江敦和慈善基金会支持下，由中心和北京新阳光慈善基金会、深圳市慈缘慈善基金会联合发起，为三家机构救助领域内的病友提供无息借款。“爱流转计划”可以让病友获得资金周转，解决燃眉之急，避免借高利贷的昂贵利息。同时希望让病友们有尊严地求助和受助，因为每一个受助者，在还款的时候又会变为施助者，让爱流转起来。

Pay it Forward Emergency Loan Scheme was co-founded by CCRD, Beijing New Sunshine Charity Foundation and Shenzhen Meet Charity Foundation with the support of Zhejiang Dunhe Charity Foundation in 2015. It provides free loan to patients supported by the three agencies.

Pay it Forward Emergency Loan Scheme provides short term loan to needed patient families in case of emergency, so they do not need to borrow money from usury. Meanwhile the plan also makes patients seek and receive help with dignity. Every recipient will become next helper once they repay the loan and make love turnover.

##### 瓷娃娃爱心病房

##### China-doll Love Ward



山东省立医院瓷娃娃爱心病房成立于2010年，旨在基于病房，系统性地为成骨不全症病友提供医疗支持。陪伴支持和教育支持，构建病友社会支持网络，精准服务；推动全人康复理念，增加成骨不全症科学治疗的普及性；加强融合教育实践，在减轻病友痛苦的同时，更好地融入社会，尽可能地恢复正常的学习、工作和生活。

The Shandong Provincial Hospital China-doll Love Ward project was launched in 2010. The objective of the project is to provide people with OI a ward based and systematic support on medical treatment, accompany and education, to establish a social support network within people with OI, to promote holistic approach, to enhance the popularity of science treatment for people with OI, to strengthen inclusive education. By integrated education lessons during the hospital stay, we help the patients better integrate into the society, and restore the normal learning, work and life as far as possible.



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## 社群互助 Community Mutual-Help



社群互助项目是基于社群本身的核心问题, 通过线上网络课程、线下活动、建立各区域互助小组等方式, 在积极病友分享与引导下, 建立病友对于自身疾病的正确认识, 积极对待自身的生活, 实现自我价值。

我们相信, 能够解决成骨不全症病友所面临的问题的人, 恰恰是病友社群本身; 我们希望改变公众对这一群体需要“全部救助”的刻板印象, 看到病友们的力量; 每一位病友平等有尊严地融入社会, 是我们努力的方向。

Through Community Mutual-Help Project, we organize online courses, offline activities and regional support groups, based on core needs of the community. Patients can learn from peers in better understanding OI, how to deal with challenges in daily lives proactively and to achieve self esteem.

We believe that people with OI are the main force in solving problems and challenges they are facing. The public stereotypes them as a powerless recipient. We want to change this public stereotype to ensure each people with OI could participant in the society with equality and dignity.

### 代表项目 THEME PROJECT

瓷娃娃全国病友大会  
China-Dolls National Conference for  
People with Osteogenesis Imperfecta (NCPOI)



瓷娃娃全国病友大会从2009年开始每两年举办一届, 是全国性的成骨不全症病友大会, 来自全国各地、各个阶层的病友家庭共聚一堂, 就自身疾病相关的问题展开讨论, 会议内容涉及到医疗康复培训、政策法律培训、心理干预及疏导、就业模式探讨、义诊以及病友

故事分享等议题, 并倡导和呼吁社会、政府以及社会对这一群体给予关注和支持。

CCRD holds China-Dolls National Conference for People with Osteogenesis Imperfecta (NCPOI) in every two years since 2009. Individuals with OI and their families gather from all over the country, discussing the issue of rare disorders during the conference. Moreover the conference includes medical rehabilitation, policy and law training, psychological rehabilitation, mental health, employment, and peer support. Additionally, the NCPOI appeals to government and public to pay attention to and support people with OI.

“小鱼儿康复成长计划” 亲子康复营  
Parent-Child Rehabilitation Camp -  
Fish Rehabilitation Development Plan



“小鱼儿康复成长计划” 亲子康复营, 针对成骨不全症病友及家庭, 通过康复工作坊、心理工作坊、水疗工作坊、亲子工作坊等形式, 让病友家长提升康复意识, 释放自我, 学会正确看待孩子, 陪伴孩子的成长; 让孩子能够及早预防肢体变形的情况, 得到及时有效的早期干预, 享受正常的社会生活。

The Parent-Child Camp is for children with OI and their families which includes workshops on

rehabilitation, psychology and hydrotherapy, and parent-child activities. The camp is expected to raise parents' awareness of rehabilitation. Meanwhile, parents could also release themselves during the camp and learn how to treat their children and better accompany their children. The final objective of the camp is to prevent children with OI from deformity of the limbs, and take early intervention to ensure children with OI a normal social life.

就业支持项目  
Employment Support Program



就业支持项目从2012年起与大型互联网企业合作, 并定向推送最新就业信息, 未来还将探索就业支持新模式, 旨在为成骨不全症病友提供适宜的就业资源。通过就业支持项目, 病友可根据自身特长和实际情况实现居家就业或走入职场, 在获得收入的同时, 锻炼职业技能, 培养良好职业习惯, 增强自立生活能力, 营造平等共融的社会氛围。

Employment Support Program aims at providing reasonable jobs opportunities to people with OI. The project works with large Internet companies and delivers job information directly to people with OI. In the future, the project will also explore new employment support model. Through the employment support project, people with OI are able to choose either

working at home or in the offices based on their needs. Jobs not only secure them with income, but will also develop their skills, abilities, and their capacity of independent living. Finally, the project will build an equal and diverse environment for all.



## 公众传播和调研倡导 Public Communication and Research



传播倡导: 通过多平台传播、线上线下宣传倡导活动、义卖、高校社区宣讲、媒体合作等多种形式, 进行公众科普和倡导, 使社会公众从对瓷娃娃群体认知的空白, 到对该群体概念的了解, 再到深度认知和互动, 最后能够形成平等接纳、多元共融的社会状态。

调研倡导: 成骨不全症群体, 因病致贫现象十分严重, 对该病的政策保障支持尚不完善, 社会救助机制欠缺, 教育与就业歧视现象突出, 患者在婚姻家庭、社会融入、教育就业等方面面临重重问题亟待解决。

中心对该群体进行深入、专项的定期调研, 将调研成果通过媒体等发布引起社会广泛关注, 并通过研讨会、两会提案等政策倡导方式呼吁政府有关部门, 在政策层面加强对成骨不全症群体的保障, 以改善其生存环境。

Communication & advocacy: through different communication platforms, online to offline advocacy events, charity bazaars, campus talks in universities and social media cooperation to deliver information about people with OI and advocate for them. It aims to educate public a basic understanding of OI, to build a platform for better understanding and further interaction between each other, in order to build a diverse, respectful and inclusive society.

Research advocacy: the illness-based poverty is a serious issue for people with OI. Moreover, pending issues like imperfect social security policy, lack of social assistance mechanism, severe discrimination in education and employment, difficulties in having intimate relationships and participating in society, make patients live even more challenging.

CCRD regularly conducts in-depth and researches on OI population. CCRD publishes research results through media to attract wide attention of the society. CCRD also organizes seminars and submits policy proposals to government. The ultimate goal is to advocate government to strengthen social security system for people with OI and to improve their living environment.

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《2013 中国成骨不全症患者生存状况调研报告》  
Research Report of 2013 Living Condition  
of People with OI in China



《2014 成骨不全症患者接受义务教育状况调研报告》  
Research Report of 2014 Compulsory  
Education Condition for People with OI in China

### 工作目标

1. 推动成骨不全症群体在医疗、教育、就业等方面的可及性;
2. 提升和发展成骨不全症群体在独立自主方面的意识、能力, 推动该群体的主体性建立;
3. 促进成骨不全症病友和家属交流、互助;
4. 倡导社会公众对成骨不全症群体的正确认知和多元共融, 提升社会各界的关注和参与度;
5. 开展成骨不全症群体相关的调查和研究, 推动政府在这一领域的政策出台。

### Objectives

1. To promote the accessibility to medical treatment, education and employment to people with OI;
2. To empower people with OI to live independently by promoting their subjectivity and life skills;
3. To facilitate communication and mutual-help among people with OI and their families;
4. To raise public awareness and understanding on people with OI and engage them to build an inclusive society;
5. To initiate and conduct researches and studies on OI and to advocate related social security policies.

