



IPOPI 4TH REGIONAL ASIAN PID MEETING

19-20 NOVEMBER 2022
KUALA LUMPUR, MALAYSIA

an **IPOPI** event

CARE FOR RARE
GLOBAL ALLIANCE EDUCATIONAL SEMINAR



SUPPORTING ORGANISATIONS



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Access to treatment

Progress and challenges in China

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PID Care China



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2 days - 205 survey results collected

中国PID患者获得治疗的优势和面临的挑战

第1题：我们的优势 [多选题]

选项	小计	比例
中国人口众多，患者数量多，能提供许多医疗数据支持。	135	65.85%
容易找到同点位基因缺陷患者，便于互相沟通。	131	63.9%
药物使用顺畅可及，主要用药（静脉注射用丙种球蛋白）医保可报销部分	96	46.83%
对比国外，中国公立医院就诊方便，不需要预约排队等候很长时间。	44	21.46%
患者组织在线沟通24H*7D免费解答关于疾病一切相关知识(包括但不限于心理疏导、人文关怀、政策咨询)。	51	24.88%
其他优势：[详细]	6	2.93%
本题有效填写人次	205	

第2题：面临的挑战 [多选题]

选项	小计	比例
确诊难。	98	47.8%
专业医生少，且没有成人专科医生（目前有专业医生的医院全国仅几家）。	147	71.71%
因地区医生缺乏治疗经验，部分患者长期用量不足，导致患者反复感染。	124	60.49%
IVIG治疗手续繁琐，且每个月重复做各项检查（检查肝肾功能、术前四项等）。	79	38.54%
没有病情管理，医院/科室之间无互通，检查报告不能共享。	68	33.17%
丙球被某些医院误为非治疗性用药（营养品），有严格的药物管控，患者因此用药受到限制、或者不能足量使用。	85	41.46%
床位紧张、住院输丙环境不安全，不能与感染病人有效隔离（容易交叉感染）。	51	24.88%
各地区丙球报销比率不一致（有的地方90%，有的地方不到50%）。	110	53.66%
医患之间沟通困难，患者/家属不知道如何问诊（医学专业性强，以及患者/家属和医生之间的文化水平差异，有的患者/家属治疗多年都不知道自己是什么疾病）。	60	29.27%
医生/医院与患者组织沟通极少，工作难开展。	43	20.98%
其他挑战：[详细]	10	4.88%
本题有效填写人次	205	



Progress



More Patients

At present, certain types of PID diseases have many more patients in China than other countries. Therefore, treatment options for these diseases are more extensive and comprehensive.



Easier Communication between patients

Through the online platform we set-up for our patients to facilitate communication, patients in the same disease group or caregivers can easily reach out to one another to share information from our survey and online chat groups.



Immunoglobulin In Stock and Partly Coverage by Social Medical Insurance

Most of the medication is in stock and available for purchase in big cities, immunoglobulin is partly covered by social medical insurance



24/7 Online Support

Volunteers from PID Care China provided 24/7 online service to patients (Including sharing disease information, policy consultation, psychological support etc)



Ease of making Appointments

Appointments for subsequent medical reviews are easy to make.



Challenges - Patients perspective



- × TOP 1: There are few PI Experts. Adult PID patients have very limited PI experts to visit. (71%)
- × TOP 2: Many doctors from local and undeveloped cities, have no experience to treat PID. Some patients cannot receive accurate and timely treatment, repeated infections are very common. (60%)
- × TOP 3: Social medical coverage for immunoglobulin differs largely from city to city, the range is from 10% subsidy to 90% subsidy. (53%)
- × TOP 4: Difficult to diagnose, Clinical immunology is not present in every hospital (47%)
- × TOP 5: Immunoglobins is classified as nutritional products(non-therapeutic drugs) in some hospitals, and there are strict drug control policies, so patients have restricted access or inadequate amount of drugs.(41%)

6	7	8	9	10
Complicated Treatment procedure 38%	Poor Doctor vs Patient cooperation 33%	Poor Doctor vs Patient communication 29%	Inappropriate treatment environment. 24%	Lack of Society support 20%

Challenges - National perspective

- 1 . Newborn screening is only available in limited cities
- 2 . Nation-wide PIDs registration is not available
- 3 . Lack of personalized treatment
- 4 . High cost of HSCT
- 5 . Lack of patient management
- 6 . Lack of support from local pharmaceutical organizations, who focus on collaboration with hospitals and not patients



Thank you for listening



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