

ANNUAL REPORT 2018-19

KOYILANDY PALLIATIVE CARE SOCIETY

Brief History

We are a purely a voluntary, nonprofit, ISO 9001 : 2008 certified organization, established at the small town KOYILANDY in Kozhikode district. It was formed to take care of the terminally ill, 'sent-away' patients, trying to alleviate their pain and making their last days a little more comfortable. Begun in 2005 with 5 volunteers and 4 patients, NEST has now 2000 plus volunteers and thousands of bed-ridden patients to look after. The Society at present carry out its activities under the 'brand name' NEST. The NEST community support was recognized by international entities like BBC. The intervention of NEST has brought about an impressive change in the lives of the patients. Our intention is to raise awareness and understanding of the needs – medical, social, practical,– of people living with life-limiting diseases and of their families. The backbone of Koyilandy Palliative Care Society is its volunteers who are more than 2000 in numbers. The cast, creed, color, political ideologies etc do not make any hindrance for us to care the needy. We work all days in a week through the home care as well as the clinic. The Society has been able to create a model community-owned organization in the area of disability and palliative care.

NEST CARING FOR CHILDREN WITH CHALLENGES

In October 2012 we started a centre for children with challenges. This unit has children with Physical disabilities, Speech & Hearing impairment, Learning disability and autism, cerebral palsy etc. Now we have 161 children getting training programs/therapies /developmental education from a team of speech therapists, physiotherapists, psychologists and psychiatrist. .

Our representatives attend the international seminars, visit international disability institutions and meet experts to take the best to our institution to improve the quality of life of our kids.

There are only a handful of institutes and special schools in Kerala which cater to children with disorders like Cerebral Palsy. Most institutes handle 35-40 children on an average, and are

dispersed across various places in kerala. Coverage of these institutes is relatively small compared to the number of children with CP in the state.

Malyala Manorama, popular daily in malayalam conducted a survey with the support of UNICEF and published a series called "arumakalaanuavarum" in February 2016 regarding the issues of disabled children and their parents in kerala. The survey introduced 5 institutes as models for providing treatment, therapy and training to improve quality of life of these children. Nest is one among the five.

We get technical support and guidance from the US institutions and hospitals like Ranken Jordan, Children's Hospital and Central Institute for the Deaf, St. Louis, USA to bring about systematic change that increases the awareness about and opportunities for individuals with developmental disabilities and to identify issues, research, curriculum, training, services and educational opportunities.

Our vision is to become a model community-based organization to inspire similar projects in different parts of the country with world's most motivated people and organizations who work in the area of Child Disability and their Psycho-Social development. We wish to establish a Group Consulting Clinic with world's renowned practitioners in the area and the invited local practitioners who also get a chance to listen and adopt the best practices from the best minds.

NIARC: (Nest International Academy and Research Centre) a new project is under construction, The Chief Minister of Kerala Mr. Pinarayi Vijayan has laid down the foundation stone of building on 29.07.17 NIARC was formed with a great mission – caring of children with special needs. The Caring unit for Children is offering rehabilitation and medical support for children with multiple disabilities and low functioning. We advocates the combination of quality and service besides collaborating with leading organizations and institutes setting up of global status in the area of differently abled lives (<http://www.bbc.com/news/world-south-asia-12352494>). We provide an exceptionally high care for the patients and have been recognized numerous times by the public for its advanced facilities and for the availability of highly professionals. There are different approaches and updated modules which can better the lives of differently abled children. We follow the global developments in this area we also collaborate with leading organizations and institutions all around the globe. We are currently collaborating with Central

Institute of Deaf, U.S and the discussions are in final stage with globally renowned RankenJordan Pediatric Rehabilitation Centre U.S and AL-Noor Training Centre in Dubai.

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MAJOR SPHERES OF NIARC

NIARC aim to address the unmet needs of the differently abled children through evidence based multidisciplinary evaluation and treatment approach and comprehensive rehabilitation along with community based rehabilitation services. Our primary objective is to provide the highest quality Pediatric rehabilitation care tailored to meet the individual physical, developmental, social, psychosocial and educational needs of each child and family.

The below listed therapies are our foremost managements and the formula of an inclusive multidisciplinary approach

Pediatric Rehabilitation OP

Pediatric Rehabilitation is the combined and coordinated use of medical, social, educational measures to retrain a differently abled child to the highest possible functional ability in relation to their age impairment and contextual factors to achieve social integration. It requires correct diagnosis, identifying functional capabilities and selecting the best rehabilitation intervention strategies with an understanding of the life of course of the disability and the continuum of care.

In NIARC we focus on Children up to age 18 with:-

- Multiple disabilities – Cerebral Palsy, Genetic syndromes, Neuromuscular and Muscle diseases, Metabolic disorders, Congenital and Acquired Spinal disorders, Traumatic Brain injury.
- Neurodevelopmental Disorders- Autistic Spectrum Disorders, Attention Deficit Hyperactivity Syndrome.
- Speech and Language Disorders
- Hearing Impairment
- Intellectual Disability

Services provided:-

- Complete Medical and Functional assessment.
- Medical guidance in goal setting and treatment.
- Early diagnosis and Intervention Clinic
- Spasticity management – Antispastics, Botox injections, Serial Casting.
- Pain management
- Medical management of ASD,ADHD.
- Prescription of Orthosis/Splints.

- Prescription of Assistive & Adaptive devices, Alternative & Augmentative Communication devices.
- Gait analysis.
- Parental Education regarding Disease, Disability, Nutrition and Architectural Barriers.
- Appropriate Referral – Co-ordinate Child's care with other Physicians (Neurologist, Otolaryngologist, Ophthalmologist, Orthopedician, Psychiatrist, Pediatrician) whenever necessary.

Physical Therapy

At NIARC, our Physical therapists work with a wide spectrum of differently abled children. The Physiotherapist who works one to one with your child will get to know them through activities before commencing any formal therapy.



Our physical therapy program includes:-

- Endurance training.
- Balance and Coordination training.
- Weight management.
- Tone management.
- Positioning
- Gait training.
- Training with Assistive devices (walker), Wheel chair training.
- Home accessibility assessments and modifications.
- Parental training and Scheduling of

- Facilitation of gross motor skills.

Home based exercise program

- Strengthening exercises.
- Range of motion exercises.
- Specific advice for positioning and carrying the child at home.
- Teach parents how to facilitate their child's movement.
- Teach Home based exercises.
- Teach how to reduce the risk of contractures and deformities.
- Advice on the use of equipment such as standing frames, parallel bars, treadmill, therapeutic ball and Assistive devices.
- We believe in developing a trusting relationship between the child, the parent and the therapist in order to maximize the therapeutic outcome.

Occupational therapy

Occupational therapy helps children live more independently with their special needs through the therapeutic use of play, self-care, learning and leisure activities.

In NIARC, our Occupational

therapists have a holistic perspective, in which the focus is on adapting the environment and/or task to fit the child who is an integral part of the therapy team. The emphasis

is on learning through enjoyable activities which also motivate the child. We aim to make the child as independent as possible in the skills he/she needs for



everyday life
through a one to
one training
program

Our occupational therapy program includes:-

- Developmental motor intervention.
 - Fine motor skill training, Hand function training.
 - Balance and coordination training.
 - Training of Activities of daily living (ADL) and Instrumental ADL.
 - Sensory integration.
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- Cognitive retraining – Attention, Concentration.
 - Oral/motor feeding and swallowing training.
 - Visual perception retraining.
 - Auditory and Vestibular retraining.
 - Rest, Sleep preparation and participation.
 - Play and Leisure exploration and participation.
 - Social participation – Family, Peer, Community.
 - Environmental adaptations and adaptive devices.
 - Home accessibility evaluations.
 - Parental training.
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Speech & Language Therapy

Speech & Language Therapy provides treatment, support and care for those children who have difficulties with speech, language or swallowing as in Speech and Language disorders , Hearing Impairment , Autistic Spectrum disorders, Intellectual disability, Multiple disability.



In NIARC, our Speech therapists work with children individually on programmes such as Picture Exchange Communication System (PECS), articulation programs and auditory

verbal therapy. We also have group therapy sessions to promote interaction, communication and social skills. These programs are individualized according to child's abilities and need

Our therapy program address:-

- Speech – articulation , voice , fluency (stuttering)
- Receptive and expressive language
- Communication
- Hearing Impairment
- Hearing evaluation
- Hearing aid / cochlear implant selection
- Counseling about care and maintenance of aids
- Auditory training
- Speech therapy
- Home training
- Regular follow up
- Pre School program
- School program – Segregation and Integration
- Augmentative and alternate communication (AAC)
- Cognition
- Language-based reading difficulties
- Oro-motor dysfunction
- Swallowing and feeding disorders
- Therapeutic listening
- Central auditory processing disorders
- Standardized developmental testing
- Parental training

Audiology Lab:-

Our dedicated space for Audiology services consists of state of the art equipment to identify the extent of hearing impairment through investigations focusing on both peripheral and central processing.

Clinical child psychology

Clinical child psychology is a specialty that develops and applies scientific knowledge to deliver psychological services to infants, toddlers, children and adolescents within their social context. our Psychologists deals with the children displaying a variety of psychological, behavioral, developmental, academic, family, peer and health-related difficulties in a variety of settings. They work with the children on one on one session, identify the problems of the child, make diagnostic formulations, and finalize the appropriate therapeutic strategies for the child by formulating the short term and long term goals.



Our Psychotherapy Program includes:

- Clinical Interview
- Psychological Assessments
- Diagnostic Formulation
- Functional Behaviour Analysis
- Applied Behaviour Analysis
- Behavioural Therapy
- Attention Enhancement Strategies

Special education

In NIARC, our Special educators work with students who have a wide range of learning, mental, emotional, and physical disabilities. They provide a continuum of services, in which students with special needs receive varying degrees of support based on their individual needs.



They adapt general education lessons and teach various subjects, such as reading, writing, and maths. They also teach basic skills, such as activities of daily living, social skills and communication techniques. Student to teacher ratios are kept low, often 10:1. Classrooms are divided according to the intellectual ability and skills of children.

Our Special education program includes:

- **Early Intervention Unit:** Human development and learning habits are most rapid in the pre-school years. For children with special needs, this is the optimum time to impact their development and if not, to negate the effects of disability and to minimize its impact. Children aged 1-4 can attend the full-time Early Intervention Class as soon as they have built up sufficient skills to be able to participate in some basic level activities.
- **Individualized Education Program:** IEP is meant to address each child's unique learning issues and include specific educational goals. It is intended to help children to reach educational goals more easily than they otherwise would. Developing an IEP requires assessing students in all

areas related to the known disabilities, simultaneously considering the ability to access general curriculum, considering how the disability affects the student's learning, forming goals and objectives that correspond to the needs of the student, and choosing a least restrictive environment possible for the student.



- Assessing students' skills to determine their needs and to develop teaching plans
 - Adapt lessons to meet the needs of students
 - Plan, organize, and assign activities that are specific to each student's abilities
 - Teach and mentor students as a class, in small groups, and one-on-one
 - Assessing students' performance, and track their progress
 - Helping in transition from grade to grade
-



Pediatric Dental

Children with special needs shows a higher risk of dental problems like dental caries, periodontal disease, dental erosions, malocclusion, bruxism, enamel defects, creating significant morbidity that can further affect their wellbeing and negatively impact their quality of life. This result from multiple factors including Intellectual disability, malnourishment, motor and coordination difficulties, gastro oesophageal reflux disease, drooling, as well as limited oral care and hygiene.

Screening for dental disease should be part of the initial assessment of any child with multiple disabilities.

We have a dedicated dental outpatient clinic, with the services of a Pedodontist weeklyonce.



Our dental services include:

- Individually tailored evaluation in a child friendly atmosphere
- Medical management of dental problems
- Minor dental procedures
- Parental training – home dental care and hygiene

We want our children to get the best. We want their families to feel empowered and to face the challenge of bringing up a special child with utmost respect and courage. We want the society to recognize these children as special and to take it as a social responsibility to empower them. By empowering we dream of ourselves, our society, our nation and the world.

FUNDS OF THE INSTITUTION

SI.No	
01	Donations from well wishers
02	Donations from Chapters abroad
03	Box collection in local shops
04	Donations of from local peoples
05	Collections from various events

STAFF DETAILS OF NEST AS ON 31.03.2019

SI.No	STAFF	DESIGNATION
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1	PRAMEELA C	ADMINISTRATIVE OFFICER
2	AMJADHA NASAR	PRO
3	BINCY T A	ACCOUNTANT
4	ATHARV J ANAND	OFFICE ASSISTANT
5	YASER AHAMED	OFFICE ASSISTANT
6	LUBNA MISAJ	RECEPTIONIST
7	SUDHA	CLEANING
8	SHANTHA	CLEANING
9	BHAVANI	CLEANING
10	SHYBHA	FIELD WORKER
11	RAJANIMOL C.K	NURSE
12	SARANYA	NURSE
13	NIMISHA K V	NURSE
14	SHINOJ	NURSE
15	REMITHA	NURSE
16	FAIZAL	DRIVER
17	FATHIMA SUHRA BEEVI	PHARMASIST
18	MOUBEENA	PHARMASIST
19	HABEEB P C	PHYSIOTHERAPIST
20	SHEKHA	PHYSIOTHERAPIST
21	RINCY	PHYSIOTHERAPIST
22	ANJANA P P	PHYSIOTHERAPIST
23	AMRAG	PHYSIOTHERAPIST
24	SHIJO MOHAN	PHYSIOTHERAPIST
25	HASEEFA	PHYSIOTHERAPIST
26	MUHAMMED ISMAIL	PHYSIOTHERAPIST
27	JUSHNA	AUDIOLOGISTT
28	JUNA	AUDIOLOGIST
29	NIHALA	AUDIOLOGIST
30	SHREYA	AUDIOLOGIST
31	GILSINA T K	AUDIOLOGIST
32	NOORUL HUDA KHASIM	AUDIOLOGIST
33	SHYIONA SUDHEER	AUDIOLOGIST
34	ALAKHA S PRASAD	AUDIOLOGIST
35	JIYA JAMES	OCCUPATIONAL THERAPIST
36	RAMYA	OCCUPATIONAL THERAPIST
37	JESNA	SPECIAL EDUCATOR
38	NIMYA	SPECIAL EDUCATOR
39	AMRUTHA	SPECIAL EDUCATOR
40	JILISHA V P	SPECIAL EDUCATOR
41	NEETHU	SPECIAL EDUCATOR
42	DIVYA C K	SPECIAL EDUCATOR
43	SIBINA	PSYCHOLOGIST
44	ARSHAKH C	PSYCHOLOGIST
45	GYIPSA	PSYCHOLOGIST
46	ANUSREE DEVADAS	PSYCHOLOGIST
47	AMITHA	HI TEACHER
48	ANU	HI TEACHER

YEARLY REPORT

THERAPY, I E P, AUDIO TEST 2018 - 2019

SL. NO	THERAPY SESSION	Student s	Session s
01	SPEECH THERAPY SESSION	121	9025
02	PHYSIO THERAPY SESSION	46	4110
03	OCCUPATIONAL THERAPY SESSION	48	1028
04	PSYCHOLOGY	82	4125
05	IEP/SPECIAL SCHOOL	69	4905
06	AUDIO TESTS		336
07	ADULT PHYSIO(HOME CARE)		1007
08	ADULT PHYSIO		3119
09	PEDIATRIC OPS(DR SOUMYA)		251

PALLIATIVE CARE YEARLY REPORT
2018 - 2019

SERVICE DESCRIPTION	PREVIOUS MONTH	CURRENT MONTH	YEARLY CUMILATIVE TOTAL
HEMECARE (NHC)	501	542	5352
NEW CASE	31	29	347
DOCTOR HEMECARE (DHC)	21	16	287
DOCTOR OP - GENERAL	205	233	2757
MEDICINE ONLY - GENERAL	346	346	4574
MEDICINE ONLY - PSYCHIATRY	76	84	1092
PSYCHIATRY			
HEMECARE	11	22	123
PSYCHIATRY OP	25	18	328
DAY CARE	25	22	348

DROP OUT	0	10	72
EXPIRED	10	30	247
BP CHECK UP	163	189	1656
CATHETERIZATION RYLES TUBE	47	65	599
INSERTION	4	3	83
GRBS	73	71`	772
BLOOD SAMPLE	14	19	116
C&D	160	161	1509
ENEMA	16	13	206
PRE	17	8	196
IVF	23	16	325
BLADDER WASH	6	6	74
INJECTION	78	44	931
EQUIPMENT SUPPORT	14	15	139

IMPORTANT EVENTS



"Make the choice to cherish your voice"

(VOICE DAY CLEBRATED BY NEST SPEECH AND AUDIOLOGY DEPARTMENT)



{A NEW ROAD INNUGRATED FOR NEST}

(NIARC BUILDING FUND 1ST INSTALMENT HANDED OVER TO ULCC CHAIRMAN BY PARRISON GROUP OF COMPANY CHAIRMAN)



UNDER THE GUIDENCE OF DR FERAZ KHAN (IAPMR) A TWO DAYS WORKSHOP ON PHYSIOTHERAPY CONDUCTED AT NEST FOR SPECIAL SCHOOL CHILDREN NEST PHYSIOTHERAPIST AND DOCTOR OF VARIOUS HOSPITAL NEAR AROUND KOZHIKODE ATTENDED THE MEETING.



(KERALA SOCIAL JUSTICE DEPARTMENT DIRECTOR NOOH P BAVA .I. A. S VISITED)



(PAINTING COMPETITION HELD FOR NEST CHILDREN AT KOYILANDY)



(VARIOUS PROGRAMMES HELD AT NEST BY SHRI ANJANYA COLLEGE OF NURSING AND NEST CHILDREN)



(DISABILITY CERTIFICATE DISTRIBUTION TO DISABLED CONDUCTED AT NEST BY CRC KOZHIKODE)



NIARC SCHOOL FOR HEARING IMPAIRED (12-06-2018) (NIARC SCHOOL FOR HEARING IMPAIRED INNUAGRATED BY MR. MOHAN, SECRETARY COMMISSION OF INDIA KINGSTEN, JAMAICA)

(DISRTICT EDUCATIONAL OFFICER VISITED NEST ON 13.07.18 IN CONNECTION WITH NIARC HI SCHOOL REGISTRATION)



(US NEST CARE FOUNDATION VISITED NEST AND TAKEN CLASSES FOR PARENTS OF NEST CHILDREN)



(MRS ISHPANA ALQUAITH DIRECTOR OF ALNOOR TRAINING CENTRE DUBAI VISITED NEST)





**(KOZHIKODE CHILD PROTECTION OFFICER
MR JOSEPH REBALLO VISITED NEST)**



(INDEPENDENCE DAY CELEBRATED)



(STAFF ORIENTATION TRAINING HELD AT NEST)

WORLD CEREBRAL PALSY DAY CELEBRATED IN NEST

**WORLD MENTAL HEALTH DAY CELEBRATED IN NEST WITH
VARIOUS PROGRAMMES**





(WORLD PALLIATIVE CARE DAY CELEBRATED IN NEST



(CAMP CONDUCTED AT NEST TO INCLUDE THE DIFFERENTLY ABLED PERSONS IN VOTERS LIST BY THASILDAR)



(CELEBRATED CHILDRENS DAY)

(NEST THERAPIST AND COMMITTEE MEMBERS VISITED CENTRAL INSTITUTE FOR DEAF USA IN CONNECTION WITH PROFESSIONAL DEVELOPMENT PROGRAMME AS THEY TAKING CLASSES FOR NEST THERAPISTS FOR LAST ONE YEAR:



WORLD DISABILITY EXPO-2018



For the celebration of World Disability Day NIARC has organized "WORLD DISABILITY EXPO-2018", at the Institution on 7/12/18. The event was organized along with the presence of Committee members and Staffs' Wall posters were exhibited in the expo, staffs from different departments highlighted their views about Disability Day. So many parents and children attended the celebration.

NEW METHODS FOR REALISATION OF OUR DREAMS

The Department of Psychology, NIARC found out a new strategy for the rehabilitation of the differently able children by visiting their homes and making individual work sheet that could help the parents to monitor the behaviour of their children at home. Clinical psychologists Arshakh, Sibina and the Psychologists Anusree and Jipsa made active role in providing guidance to the parents....



Visit Of Deputy Director Of

Education



Rankan Jordan Pediatric Bridge Hospital,USA Video Conference



Dr Soumya Viswanathan, the Medical Director of NIARC attended online discussion with Dr Nicholas A Holekamp of RANKAN JORDAN PEDIATRIC BRIDGE HOSPITAL,USA, regarding the latest technologies and methodologies available in United States,to implement the same in Nest International

Academy And Research Centre.



NIARC organized parents meeting on 16.01.19 for all the parents from each department. The meeting was all about Students Attendance, Home works, Leave policies of students, Home based programmes and our new family Centre (24*7).The meeting was well attended by the parents

Republic Day



The historical day to remember the national heroes and freedom fighters, who suffered to give us a republic nation, 70th Republic Day was celebrated in NEST/NIARC . Administrative officer Smt. C.Prameela hoisted the National Flag during the occasion and All NEST staffs and children were

present in the function.

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Dr. Soumya Viswanath
Rehabilitation Specialist and Medical
Director of NIARC has visited
Alnoor Training Centre Dubai to find
out the new learning methods and
ideas and to implement the same to
NIARC.



The NIARC building fund is handovering
to ULCCS Chairman by NIARC Global
Vice chairman Mr. T.K. Abdul Nasir



The NIARC building fund has been
handed over by Mr. T.T. Muhammed Ali of
Baharin Chapter to NIARC Treasurer in
presence of Mr. Abidkutti, Mr. Ahamed,
Mr. Susanth.

9

A friendly visit indeed a warm moment. Mr.

Ajith (Treasurer NAMMA) USA visited NEST on 28.03.19. NIARC/NEST committee members received him and explained the functioning of the organisation.



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**(VISIT OF NEST STAFF AND COMMITTEE MEMBERS TO AL NOOR TRG CENTRE DUBAI
IN CONNECTION WITH PROFESSIONAL DEVELOPMENT PROGRAMME.)**

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