

## ON THE OCCASION OF CAME: ALL INDIA CONFERENCE OF CAREGIVERS OF PERSONS WITH MENTAL ILLNESS

Dr. Jagannath Wani is well known to the Marathi-speaking population as the person responsible for generating financial support to the lower echelons of the society. But a lesser known yet important aspect about him is that he was a family member and caretaker of a mentally ill person, his life-partner. Dr. Wani migrated to Canada for higher studies in the sixties. From 1972, his wife, Kamalini, began experiencing symptoms of schizophrenia. Like any other devoted family man, Dr. Wani was confused at first. For the next 8-10 years Dr. Wani single-handedly faced all the ensuing uncertainty and unease.

Through this battle, he met many persons who literally became lighthouses in his stormy journey.

Dr. Rocksberg told him in no uncertain terms that he was not to blame for his wife's condition. This statement brought him immense relief and ended the uneasiness in his life. Dr. Wani was inspired by Bill Jeffrey who had multiple family members suffering from mental illnesses. Jeffrey did not give in to his grief but instead channelized it into helping others.

He travelled all over Canada, delivering lectures and focusing on the need for support groups of the family members of the mentally ill. One of these lectures inspired Dr. Wani to establish the 'Schizophrenia Society of Alberta'. After working in Canada, he realized the need for such groups in India as well. This noble urge

contribution to the cause and to propagate his exalted work. This conference will seek and ensure participation of the well known experts from all over India as well as the founder members of the family support groups. This is an attempt to strengthen the familial participation and carry forward the legacy of Dr. Wani. To begin

with, two important issues placed before this Conference are :

1 - 'Challenges that face the family members of the mentally ill.'

Family members face a turning point when serious symptoms of the illness start manifesting themselves. These challenges are uncertain, which makes matters worse. Information and the support of fellow-sufferers

is invaluable, both for physical and mental illnesses. But the absence of visible symptoms in mental illnesses, the uncertainty of the symptoms and sheer lack of knowledge about the illness are the various reasons for the need of groups or institutions for the families of the mentally ill.

While facing such a situation,



made him establish Schizophrenia Awareness Association in Pune with help from his close friends-cum-college-mates.

Tenth September is Dr. Wani's birthday. On this day, SAA has decided to organize an All India Conference for family members of the mentally ill (CAME ) in commemoration of Dr. Wani's

the families need the support of experienced individuals and groups. On the local level, an institution comprising of parents can take up this responsibility. Of course, it is important that the local institution is strong and has able volunteers. It's also very important to focus on awareness, self-help groups, rehabilitation and the less expensive options. The number of family oriented organizations has to increase and those already in existence should expand their horizons and show qualitative improvement. Many organizations have limited themselves to a small group within families. Students from schools and colleges, senior citizens and various social organizations should identify with this problem. This will ensure that these organizations get social sanction and avoid the limitations that their narrow perspectives have confined them to.

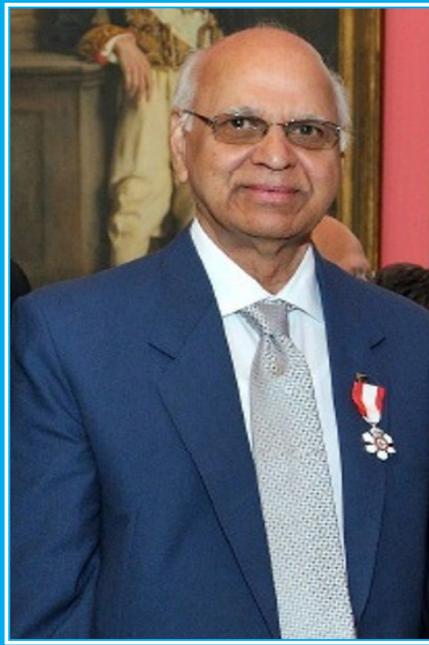
2 - 'The success & failures of organizations for the family members of the mentally ill.'

To be united and effective India needs a federation of the local support groups for parents and such institutions that exist all over India. As in the setup of a federal government & state governments, local caregivers' groups should attend to and resolve problems they face and leave the federation to deal with problems that are pan-India. However, this seems easier than the problems that crop up. In India the number of organizations that function at the local level are neither sufficient, nor completely enabled nor effective.

Organizations working for the cause of physical illnesses have a history of over 80-90 years, while those grappling with mental illnesses are barely 30 years old.

But the main problem is, the movement against mental illness is not organized. There are many different opinions and ideological differences that limit even the formation of policies and laws regarding mental health.

In India an attempt has been going on since 1995 to establish



an all India organization for the parents of the mentally ill. Many officials of SAA have been closely involved with this movement from the beginning. Many conferences were organized on an all India level as well. But even today, a culture that recognizes the need for Pan India Organization has not been established. Six years' ago an organization called FAMILIES ALLIANCE ON MENTAL ILLNESS National Network (FACEMI NN), a federation for parents was started, but much more remains to be done at the national level. It is important that family based organizations also be strengthened at the state levels. This would, in turn, strengthen organizations at the national level.

Taking into account the sheer spread of our country, it would

be useful to have separate zones like, say, North, East, West & South, instead of just one single national organization, operating only from a single city. This will eliminate the problems caused by distance. This will also help disseminate information effectively through audio-visual mediums about rehabilitation and other services. The separate zonal organizations will be able to work better on the local level and improve the working of the organizations. In a country like India, where there is a paucity of funds, a strong well-spread network of such organizations is a must.

This Conference planned for Tuesday the 10th September at Pune will see the participation of parents and experts from the field of mental health from various parts of the country, to review the challenges that parents and parents' organizations face. Narrating their experiences, discussion and guidance will enable these parent organizations to move and grow in the right direction. Let the 'lighthouses' that Dr. Wani dreamt of be turned into a pleasant reality so that they enlighten and guide more and more parents' organizations.

#### **Anil Vartak, Ph.D**

(The author is the Vice President of the 'Schizophrenia Awareness Association' **SAA** Pune.)

avartak@yahoo.com  
+91 95037 10859

Originally Published in  
Dainik Herald, Panaji, Goa.  
(5/9/2019)

English Translation by  
**Ms. Dipali Lodh**

Graphic Support by  
**prithvigraphics.com**

## DR. JAGANNATH WANI: A COMPREHENSIVE CAREGIVER

Dr. Jagannath Wani is well known to Marathi speaking population as the person responsible for generating financial support to social organizations working for the lower echelons of the society. But a lesser known yet important aspect about him is that he was a family member and caretaker of a mentally ill person, his life-partner. Dr. Wani migrated to Canada for

his youngest son, Raju shared a very different relationship. On one end, the youngest child was the co-caregiver in his mother's illness and at times, when she was upset with his father, the only caregiver. Talking about his mother, Raju Wani says, 'I remember, when I was very young, one night, around midnight, my mother came out of the house and began shouting and

Rocksberg told him in no uncertain terms that he was not to blame for his wife's condition. This statement brought him immense relief and ended the uneasiness in his life. Dr. Wani was inspired by Bill Jeffrey who had multiple family members suffering from mental illnesses. Jeffrey did not give in grudgingly to his grief but instead channelized it into helping others. He travelled all over Canada, delivering lectures and focusing on the need for support groups of the family members of the mentally ill. One of these lectures inspired Dr. Wani to establish the "Schizophrenia Society of Alberta". After working in Canada, he realized that the need for these groups existed in India as well. This made him form the Schizophrenia Awareness Association in Pune.

After starting his work in the field of mental health, Dr. Wani soon moved on to working for other deprived sections of the society in Maharashtra. Dr. Wani used to say very often 'I have read stories of Sane Guruji from my childhood. It might be known as gloomy literature, but the kindness in it always appealed to me.' This stirring of kindness in me may have inculcated the desire to work for the deprived sections of the society. Every organization needs committed volunteers, but if such volunteering is supported with financial aid, it qualitatively contributes to the growth of the cause. Dr. Wani recognized and identified this need and



higher studies in the decade of the 60s. From 1972, his wife, Kamalini, began experiencing symptoms of schizophrenia. Like any other devoted family man, Dr. Wani was confused at first. For the next eight to ten years Dr. Wani single-handedly faced all the ensuing uncertainty and unease.

The journey was very difficult. He had three school-going children at home. Apart from their upbringing, he had his responsibilities at the University and the ups & downs of Kamalini's symptoms. He and

ranting about irrelevant things. The illness had her in its grip and she did not know what she was doing. My father peacefully calmed her down, reasoned with her and brought her back inside the house. At that time, if he had over reacted, the situation would have been out of control! In his future life, Dr. Wani was to weather many such storms with immense control.

Through this stormy battle, he met many people who became lighthouses in his journey. Dr.

extended a helping hand through the Maharashtra Seva Samiti Organization and CIDA. He brought in foreign aid of around eight million dollars to help about 30 organizations working in Maharashtra. But he was always humble by describing himself only as a 'glorified telephone operator' connecting the organizations with the funding agencies.

Dr. Wani never paid attention to the ideology of people behind the organizations while offering financial support or aid. 'The organization should be Indian and do good work.

That's all I can see from a distance of over 10,000 miles,' is what he would say. Many individuals are impressed by a particular ideology, stick to it using the same parameters in all situations and prefer to stay within their comfort zone. In Maharashtra, which was used to this mindset, Dr. Wani's broader outlook was welcomed like a whiff of fresh air.

Dr. Wani's support to social organizations was all-encompassing. Right from gathering funds to solving organizational and personal problems, he would willingly accept all such responsibilities. This generous attitude ensured that all the organizations he helped made progress. The visible aspect of any person's work is always acknowledged. Dr. Wani's work, like any others' work however, was like that of an ice-berg.

Ninety-percent of this- efforts and perseverance for this work were invisible. Usually, the visible aspect is appreciated. But the hard work that goes into establishing so many organizations, gathering manpower, addressing them, completing the formalities of establishing a new organization,

But he was also aware of his other responsibilities. This commitment to one's responsibilities yet remaining detached ensured his success not only in his teaching profession and research but also in the various social responsibilities that he willingly undertook."



Speaking about his father's last journey, his son, Raju Wani became emotional when he said, 'My father took care of my mother till the very end. She had cancer and my father had Stage IV cancer as well. Even in these circumstances he catered to her every need. If

recognizing the important aspects of what the organization deals with and furthering those aspects, locating sponsors for financially aiding other organizations, using his statistical and logical skills to generate aid; are all very inspiring and unique qualities of Dr. Wani, worthy of emulation.

The Ex-President of SAA and a close associate of Dr. Wani, Mr. Yashwant Oak still gets emotional when speaking about him. He says, "I first met Dr. Wani at his residence in Calgary. As a family member of a patient, a husband, he took excellent care of his wife. He also deliberately avoided irritation, complaining to others about his difficulties and letting them affect other aspects of his life. He carefully cultivated this attitude of detachment. He accepted that tending to his wife was a very important responsibility in his life.

he didn't know how to make a certain dish, he would even call up his sister in India and learn new recipes from her. Looking at his advanced stage of illness, I would tell him not to worry and that I would take care of my mother if and when necessary. But till her death, apparently he managed to stall his own demise. He was a caregiver to his wife till the very end. Till the last stage of his life, he did not forget or ignore the needs of others or lose his will to help out. In his final days he even donated two life insurance policies to two universities: to the McGill University, from where he did his PhD and to the Calgary University, where he taught. He repaid his debts to both the motherland and the land where he established himself.

Every person's life is a journey, the journey of life. Man is born with

certain innate qualities. But these may not be enough for a lifetime. Everyone has to decide the direction and speed of one's own journey. In this journey, it is very important how one responds to the incidents that occur all around and also to the people one meets. Dr. Wani always gave the example of Stephen Covey. The success or failure of any event or venture depends on the reaction, rather than the action. Ninety percent of the end result depends on one's reaction. This was the mantra that Dr. Wani followed all through his life and it resulted in an amazing body of work on the personal and

social levels despite the difficulties that plagued him.

Tenth September is Dr. Wani's birthday. On this day SAA has decided to organize an All India Conference for the family members of the mentally ill to acknowledge Dr. Wani's contribution to the cause and also to propagate his work. This Conference will see the participation of well-known experts in mental health from all over India as well as the founder members of family support groups. This is an attempt not only to strengthen the familial participation but also pay a nationwide tribute to his memory

by carrying forward the legacy of Dr. Wani

**Anil Vartak, Ph.D**

(The author is the Vice President of the 'Schizophrenia Awareness Association' **SAA** Pune.)

+91 95037 10859

avartak@yahoo.com

Originally Published in  
Maharashtra Times,  
Pune.(8/9/2019)

English Translation by  
**Ms. Dipali Lodh**

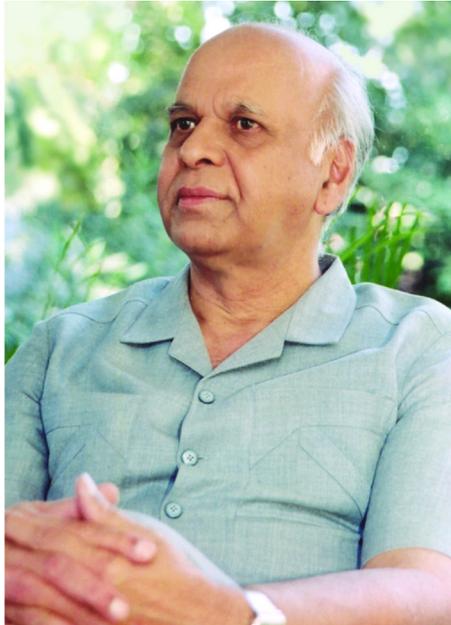
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## Dr. Jagannath Wani: The Staunch Supporter of Social Organizations

Dr. Jagannath Wani, an important figure in the field of social and mental health in Maharashtra basically hailed from Dhule. He travelled to Canada to pursue higher education. He taught Statistics at Calgary University for many years. A few years after his marriage, his wife Kamalini, had to confront a major mental illness: schizophrenia. This was the decade of the 1960s. Treatments for mental illness were still in the dark. Today, in the second decade of the 21st century, treatment, medication and awareness have increased manifold.

If we imagine Dr. Wani's plight at that time, it is evident that Kamalini's illness affected him as well. His personal life, the problems that arose, the neglect his children faced, the stress of looking after the family and coping with the pressures of work, all together must have taken a toll on him. Despair and indecision must have enveloped him at various times. But



when the going gets tough, the tough get going. This was true in Dr. Wani's case. Such people do not only find solutions for themselves but also try to ensure that others do not have to face such situations; and if they have to, look for ways to make the situation more palatable for them. Dr. Wani says, "Some individuals have overcome their own grief to extend a helping hand towards others. It was because of them that I was able to remain strong and achieve my dreams. There were always lighthouses to guide me through the fearful seas."

And then, another lighthouse was born.

Many individuals try to accomplish what Dr. Wani did, but the perseverance, organizational skills and decision making abilities that are required for the same were qualities that Dr. Wani inculcated and cultivated. The famous journalist Kumar Ketkar says, "Dr. Wani's journey from darkness to light is full of vicissitudes and disappointments. This journey is personal but not person-oriented." This is why and how Dr. Wani channeled his personal pain and created various social organizations. A meaningful existence is never accidental; it has to be planned and executed, was the thought that Dr. Wani focused on. This gave birth to the 'Schizophrenia Awareness Association', an organization working for mental health.

One dream was fulfilled and a



new one was born. This is true of all determined and focused people. Fulfillment of a dream does not imply the end of their journey. It just enables them to follow the next dream. After 'SAA' was established, he started looking for ways to strengthen the organization. Finance is an important cornerstone for the growth of any social organization and Dr. Wani was an expert at generating funds for organizations. He was responsible for the establishment of around 18 odd social organizations in Maharashtra. Dr. Wani worked tirelessly, day and night, to send the details of the organizations to funding agencies answer their queries and improve the projects. This generated the expansion of all the projects. Dr. Wani travelled all over Maharashtra, following up on the various projects and this is the reason why all the projects have been contributing extensively to social improvements. His invaluable contribution was

recognized and rewarded when the Government of Canada awarded him the 'Order of Canada', the highest civilian award.

The Ex-President of SAA and a close associate of Dr. Wani, Mr. Yashwant Oak still gets emotional when speaking about him. He says, "I first met Dr. Wani at his residence in Calgary. As a family member of a patient, a husband, he took excellent care of his wife. He also deliberately avoided irritation, complaining to others about his difficulties and letting it affect other aspects of his life. He carefully cultivated this attitude of detachment. He accepted that tending to his wife is a very important responsibility in his life. But he was also aware of his other responsibilities. This ability ensured his success not only in his teaching profession and research but also in the various social responsibilities that he willingly undertook."

Dr. Wani, who worked for

financially enabling social organization, and travelled all over Maharashtra for over two decades, is not with us today. In a way, the sun has set on the era of Dr. Wani, but his thoughts and philosophy live on. His hard work over the years had taken roots in various soils and terrain. Much like the strong supportive oak tree that does not suddenly crop up in a flourish of trumpets but grows slowly and silently, individuals like Dr. Wani remind us that the wait for this tree is worth it.

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Vice President, Schizophrenia Awareness Association  
9503710859  
avartak@yahoo.com.

Originally published in  
Dainik Herald, Panaji, Goa.  
(15/11/2018)

English Translation by  
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