

The Alliance Advocate

NAMI San Diego--San Diego's Voice on Mental Illness

Formerly San Diego Alliance for the Mentally Ill

April 2002

Volume VI, Issue 4

A Consumer's Perspective on Psychiatric Research

By Shannon Flynn

Shannon Flynn is a mental health consumer, a research assistant for the National Institute of Mental Health in the Clinical Brain Disorder Branch, and an art therapist.

Shannon is also a public speaker who

I have found that consumers participate in psychiatric research for a variety of reasons. Some have altruistic motives – wanting to further biomedical knowledge about their illness or about the efficacy of a certain treatment. The hope of trying a new medication, financial compensation, and greater understanding and control of an illness also motivate psychiatric consumers.

Some of us have a combination of motives. In 1993, I participated in a clinical trial to establish the efficacy of risperidone as compared to clozapine, with the hope of switching medications as a way to remediate severe side effects and avoid the weekly blood tests required with clozapine. I also participated in a 1996 sibling study to help researchers learn more about schizophrenia and for the financial compensation. As a high-functioning consumer in recovery, I feel almost a “duty” to contribute to efforts that will help others who have not been so lucky but have no interest in “greater-than-minimal-risk” protocols.

(Continued on page 7)

Education & Advocacy Meeting

6:30 p.m. Social Hour

7:00 p.m. Business/Advocacy

7:30 p.m. Program as Follows

Mark Refowitz, Director of Adult Mental Health Services for San Diego County, will tell us :
“Whats New and Why”.

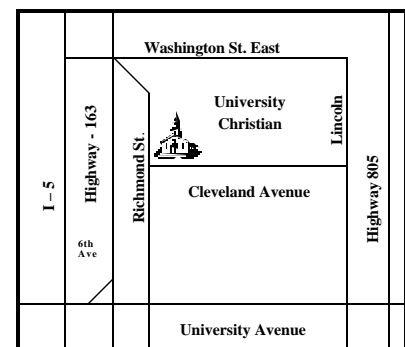
Coming Attractions:

May 2nd, 2002

Kristin Cadenhead, M.D.
of the UCSD Department of Psychiatry

Will talk on “Schizophrenia: Prodromal Stage, and Update on Early Identification

The monthly meeting is open to anyone interested in learning about mental illness. The meetings are held on the first Thursday of the month at University Christian Church, Friendship Hall, 3900 Cleveland Avenue San Diego, California (see map)



Additional NAMI meetings in the San Diego County area are listed on Page 5

Our New Home

If you weren't there, you would not believe the difference a few hours and 35 volunteers – with their hand trucks, refrigerator dollies, autos, vans, and trucks – can make. Professional movers took a load of our heaviest furniture to the new office on Friday but that still left all the boxes, computers, miscellaneous bulletin boards and other odd shapes, AND some furniture to greet volunteers on Saturday at 9 a.m. They took it all and they put it in place in the new building. What an experience! Thank you to all who were there on Saturday, that came earlier in the week to pack the boxes and that came after Saturday to unpack the boxes. An especially big thank you to members of The Meeting Place who did an impressive job of assisting us. Don't forget them if you have a moving job, they have a truck and do moving as a consumer-run business.

Come visit us at 4480 30th Street. See map on page 3.

May is Mental Health Month

Mental Health organizations throughout the county will be hosting special events during May - and a bit of April and June. Do look for these events. If you know of any that we can list in our May newsletter, please let me know.

Mental Health Recognition Dinner

This traditional event that celebrates the dedicated mental health workers, paid and unpaid, providers and consumers, as well as the supporting members of our community is the place to be the first Friday evening in June. See the flyer in this newsletter. We would love to have you join us at the NAMI San Diego table, call a number at the end of this article for details.

**WANTED
Family-to-Family Teachers**

Remember when you took the Family-to-Family class and you said, "I would like to teach this class?" This is your chance. NAMI North Coastal is sponsoring a class right here in San Diego County. Call me IMMEDIATELY for more information and to get your name on the list. Space in the

Call the Albright Center, 800.523.5933 for more information and to register.

To register your opinion on any of these issues, call Bettie Reinhardt at 294-9941 or write to P.O. Box 710761, San Diego, 92171 or fax to (619)543-1498 or email at exudir@namisandiego.org or contact

Scheduled Classes

NAMI CARE Facilitators

April 12 – 14
Location to be announced

POSTPONED

Family-to-Family

February 20 – May 8
VA Hospital
Families of VA Clients

FULL

March 4 – May 20, 2002
Gethsemane Lutheran Ch
Serra Mesa

FULL

April 1– June 24, 2002
Health Services Complex,
Riverside Ca.

**Schizophrenia: Education
for Families & Caregivers**

February 26 – April 2, 2002
In Our Own Voices
April 9, 2002
Grossmont Hospital

Peer-to-Peer

Coming soon!
**CALL NOW to get your
name
on the interview list.**

The Alliance Advocate

NAMI San Diego is a nonprofit organization that provides self-help advocacy, education, services, and support for consumers, families, and friends of people with severe mental illnesses and is dedicated to eradication of those mental illnesses and to improvement of quality of life of those affected by these diseases.

NAMI San Diego is an affiliate of
NAMI and NAMI California

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Articles received by the 15th will be considered for publication in the following month's newsletter.

The opinions expressed in the newsletter do not necessarily reflect those of

A MESSAGE FROM THE PRESIDENT

On March 12, 2002, I attended a luncheon featuring Dr. Kay Redfield Jamison. Dr. Jamison is professor of psychiatry at the Johns Hopkins University School of Medicine, author, lecturer and researcher. She was diagnosed with Bipolar Disorder in her late teens and has devoted much of her professional life to support, advocacy and awareness. Dr. Jamison's books include "Unique Mind", about mania and "Night Falls Fast", about suicide.

The topic: Women and Depression.

The scene: Filled to capacity grand ballroom at the Hyatt Regency, La Jolla.

The attendees: Family members, professionals, consumers, and mostly females.

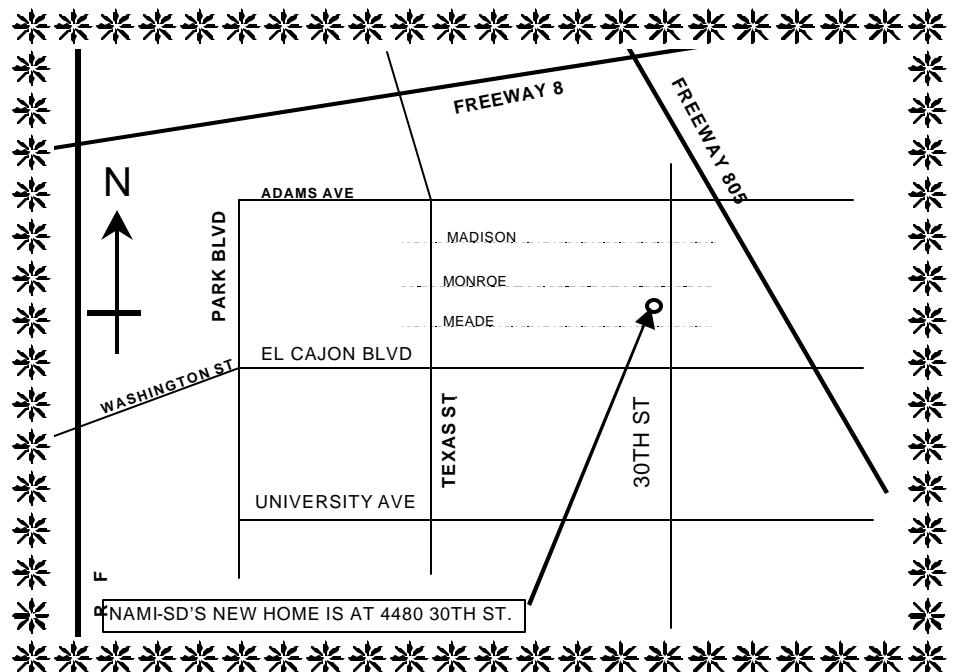
The gist: Consumers need to educate themselves, get second opinions, seek appropriate treatment and get support.

"NAMI is a great organization. We are very active in legislation, advocacy and education. Your NAMI in California is extremely active in legislative issues."

On March 12, 2002, Andrea Yates was found guilty of murder of 3 of her children.

On March 15, 2002, Andrea Yates was sentenced to life in prison. A minimum of 40 years must be served.

Don't let our education, advocacy and support end.



SAVE THE DATE!

Coming June 15, 2002, the Annual NAMI-SD Walk-A-Thon! "Strides for Mental Health: Building Healthy Minds and Bodies"



Planning is underway for our fund raiser Walk-A-Thon, to be held in Balboa Park on Saturday, June 15, 2002.

The Walk is scheduled to begin at 9:00 a.m. It will start at Laurel Street and proceed along 6th Avenue.

Pledge sheets will be available at the beginning of May to sign up sponsors.

A great Resource Fair is being planned with lots of vendors, information and fun.

Keep those tennis shoes handy!

Did you know?

The most shocking thing about mental illness is how little people understand it.

I Am Not Sick, I Don't Need Help!!

This immensely popular and even more immensely useful little book is available by loan from the Albright Center or yours to keep for a contribution to NAMI San Diego of

Legislative Update

April, 2002

by Caroline Hamlin

Shelter Plus Care Renewals

On November 26, President Bush signed into law the HUD funding package for FY 2002 (HR2620). In a significant victory for supportive housing, this bill included full funding for Shelter Plus Care renewals.

Supportive Housing Victory

In a landmark endorsement of supportive housing, this year's federal budget for the Department of Health and Human Service (HHS) includes a \$400,000 earmark for the Corporation of Supportive Housing (CSH) to work with communities on providing mental health and substance abuse services in supportive housing. This year's HHS budget includes significant increases for other targeted homeless programs representing an overall 21% increase above last year.

The targeted homeless programs that will benefit from the increase include:

- ◆ Homeless Veterans Reintegration Project (up from \$17.5 million in FY '01 to \$ 18 million, and to 25 million in FY '02).
- ◆ Health Care for the Homeless (up from \$100.5 mil. to \$113.4 mil.)
- ◆ Projects for Assistance in Transition from Homelessness (PATH) (up from \$36.85 million. to \$39.85 million.)
- ◆ Targeted Addiction Program (up from 10 mil. to \$19 mil.)
- ◆ Transitional Living Program for Runaway and Homeless Youth (up from \$69.1 million to \$88.1 million.
- ◆ Education and Homeless Children (up from \$35 million. to \$50 million.)

The above information was taken from the Corporation for Supportive Housing newsletter

AB 2034 Update

According to Ms. Adrienne Berlin, project manager for AB 2034, the San Diego Integrated Service Program, whose aim is to reduce homelessness among the mentally ill in the downtown area, the program is a success. 2034 provides case management, rehabilitation, and recovery services, physical health services, and housing. Organizations who partner in this program are Telecare Corporation, Community Research Foundation, Episcopal Community Services, Family Health Centers, Catholic Charities, Probation Department, HOT Team/SD Police Department, and County of San Diego Mental Health Services. Among other accomplishments Ms. Berlin reports that in the past year homeless episodes decreased by 90%, incarceration days decreased by 68%, and hospital days decreased by 62%. More than 200 people are enrolled in the program.

Schedule of Meetings

NAMI SAN DIEGO
University Christian Church
3900 Cleveland Ave., San Diego
Call (619) 543-1434 or
1-800-523-5933

First Thursday of each month.
See page 1 for information about this month's program.

Evening NAMI-SD Support Group
Third Thursday, 6:45 p.m.
Note New site, 4480 30th Street

Morning NAMI-SD Support Group
Third Tuesday, 10:00 - 12:00 a.m.
Note New site, 4480 30th Street

**Sharp Mesa Vista Hospital
Sharing and Caring**
Fourth Thursday, 6:30 – 8:30 p.m.
Executive Conference Room
Sharp Mesa Vista Hospital
7850 Vista Hill Avenue (858) 278-4110

Sibling and Adult Children's Group
Second Wednesday, 7:00 - 9:00 p.m.
Scripps Well Being Center
Adjacent to the UTC Mall
Call Monica Astorga at (858) 483-9370

Clairemont Area NAMI Support Group
Second Monday, 7:00 - 8:30 p.m.
St. David's Episcopal Church (Library)
5050 Milton St., (619) 276-4567

La Jolla NAMI Support Group
First Tuesday, 7:15 - 9:00 p.m.
La Jolla Presbyterian Church Lounge
7715 Draper Avenue, (858) 457-5057
(Entrance on Kline St.)

El Cajon (East County)
Second Wednesday
6:30–8:00 p.m.
562 E. Main St., El Cajon,
Forough Douraghi: (619) 401-5440

South Bay—Spanish
Fourth Monday, 6:00 - 8:00 p.m.
Call Luz Fernandez
(East County clinic)
for location (619) 401-5500

La Mesa
Second Thursday, 6:30—8:00 pm
San Carlos Library,

**NAMI NORTH INLAND
SAN DIEGO COUNTY**
P. O. Box 300386
Escondido, CA 92030-0386
(760) 745-8381

Second Tuesday each month, 7:00 pm.
Education Meeting
Bradley Center (Kinesis North)
474 W. Vermont Ave, Escondido
(760) 745-8381 or 1-800-523-5933

**On April 9th at 7 pm our speaker will be
Roberta J. Robinson, Attorney at Law
Who specializes in Probate, Estate Planning,
and Trust Law.**

The Topic will be:
“How to Protect our Loved Ones When we
are no Longer Here”
• **Bring your questions**
The public is invited to attend.
Free NAMI newsletter available
For further information please call
(760) 745-8381

Share & Care
First, Third, Fourth (& possibly Fifth)
Tuesday of each month.
4:00 - 5:30 pm. at Joslyn Senior Center
210 East Park Ave, Escondido
Call (760)745-8381

New Share and Care Meeting
First, Third, Fourth (& possibly Fifth)
Monday of each month.
Starting at 6:30 p.m.

~~Palomar Pomerado Behavioral Health Bldg~~
1540 East Valley Parkway, Escondido
Call (760) 745-8381 for further information

NAMI PATTON
c/o Patton State Hospital
3101 E. Highland Avenue
Patton, CA 92639
Fax: (714) 963-9961

Third Sunday, 11:45 a.m. - 1:15 p.m.
Administrative Meeting Room
3101 East Highland Avenue
Patton, CA (909)425-7000

**NATIONAL DEPRESSIVE &
MANIC DEPRESSIVE ASSOCIATION**
Call (800) 826-3632
for meeting places and times.
San Diego-La Jolla Chapter
Sponsored by
Dr. John Kelsoe, UCSD
Every Monday at the VA Hospital La Jolla,

**NAMI NORTH COASTAL
SAN DIEGO COUNTY**
P. O. Box 2235
Carlsbad, CA 92018
(760)722-3754

St. Michael's by the Sea Episcopal Church
Parish Hall, 2775 Carlsbad Blvd.
(760) 722-3754 or (800) 523-5933

Third Wednesday, 7:00 p.m.
**Education Meeting followed by
Share & Care at 8:40 p.m.**

**For April 17th the education meeting topic
will be**
“....because children are the future”

The speaker will be: Saul Levine, MD
Chairman, Dept of Psychiatry, Children's Hosp
Dir, Inst. of Behavioral Health, Children's Hosp.
Prof. & Dir., Child & Adolescent Psychiatry, UCSD
Program Dir, UCSD Child & Adult Psychiatry Svcs

Share & Care
Fourth Tuesday - 5:00-6:30 p.m..
North Coastal Mental Health Center
1701 Mission Avenue #A, Oceanside
(760) 967-4475 or (760) 722-3754

Share and Care
Second Thursday at 6:00 - 7:00 p.m.
Tri-City Medical Center, Mental Health Unit, 4002
West Vista Way
Oceanside (760)940-5700

Pastoral Share & Care
Fourth Thursday - 7:30 p.m.
2807 Ocean St., Apt. 301, Carlsbad
~~Jane or Tim Hird, (760)435-2536~~
Call first for security reasons.

Spouse Support Group
First Thursday of each month
6:30—8:30 p.m.
~~St Michael's Episcopal Church~~
Carlsbad

**TARA Borderline Personality Disorder
Support Group**
1st & 3rd Wednesday monthly
Carlsbad Community Church
3175 Harding Street
Carlsbad CA 92008

Client Corner

IN OUR OWN VOICE

A recovery-education program presented by trained consumer presenters/facilitators to other consumers, families, friends and professionals.

It is for anyone who needs to know how people with schizophrenia and other serious mental illnesses cope with the realities of their disorder while recovering and reclaiming productive lives with meaning and dignity.

If you are interested in training as a presenter or attending a presentation, please call:

Kamala Castle
At 619 584-5568

Always wear a Silver Ribbon™

- To show you care about someone with a brain disorder!
- To help break down the barriers to treatment and support!
- To help eliminate the stigma against those who suffer!
- To show you believe there is HOPE through education and research!

The Access & Crisis Line

1-800-479-3339

24-hours a day 7 days a week

- Professional counselors
- Multi-lingual capability
- Spanish speaking counselors

The Consumer Center for Health Education and Advocacy

If you need help getting mental health care services, please call or write us. We are ready to help you.
1475 Sixth Ave., 4th Floor
San Diego CA 92101
1-877-734-3258 Toll Free

The Meeting Place, Inc.

4034 Park Blvd., San Diego
(619) 294-9582
Open Monday - Saturday
10:00 am. - 4:00 p.m. *Monday to Friday*
11:00 am - 3:00 p.m. *on Saturday*

Corner Clubhouse

2852 University (at Utah)
San Diego (North Park) #7 Bus Line
(619) 683-7423
Open Monday - Friday
8:00 a.m. - 4:00 p.m.

Friend to Friend

1009 "G" Street
San Diego
(619) 238-2711
Open Monday - Saturday
10:00 a.m. - 6:00 p.m.
A peer advocate is available
Thursday, Friday (morning) and Saturday

Mariposa Clubhouse

560 Greenbrier, Suite .102, Oceanside
(760)439-6006
Open Monday - Friday
8:00 a.m. - 4:00 p.m.
Open Saturday & Sunday
10:00 a.m. - 2:00 p.m. *Brunch*

Friends

144 Copper Ave. Vista
(760) 941-2153
Open Saturdays
1:00-4:00 p.m.

East Corner Clubhouse

562 East Main St., El Cajon
(between Mollison and Avocado)
(619)401-6902
Fax: (619)401-1751
Open :
Mon., Tue, Thur, Fri.
8:00 a.m.- 2:00 p.m.
Wednesday 8:00 a.m. - 6:30 p.m.

Saturday - 10:00 a.m. - 2:00 p.m.

Visions @ 5th and H

499 "H" Street, Chula Vista
(619) 420-8603
Open Mon., Wed., Fri., Sat.
Noon - 7:00 p.m.
Sun. -- Noon - 5:00 p.m.

Scholarship Funds

Call the Allbright Center for information about scholarship funds.



Consumer Peer Support Groups

See the announcement on Page 3 regarding peer support groups for Consumers

Employment Services

1202 Morena Blvd., Suite 201
San Diego, (619) 276-8071

The Access Center of San Diego

1295 University Avenue
San Diego, (619) 293-3500

The Creative Arts Consortium

P. O. Box 3053
San Diego, CA 92163-3053
Admin—Call Jane (858) 481-7069
Art—Call Michelle (619) 589-2434
Literature—Call Jim (619) 299-1753

Job Options

2727 Camino del Rio South
San Diego
(619) 688-1784 (Valorie)
Open Monday - Friday
8:00 a.m. - 5:00 p.m.

San Diego Parks and Recreation Disabled Services Program:

Ask for "The Leisure Seekers" group activities and calendar. No formal registration. Simply call ahead of event and say "I want to sign up for the event"
(619) 525-8247

Patient Advocacy Program

5384 Linda Vista Road, Suite 304

(Continued from page 1)

When consumers think about research, we tend to assume it means medication trials involving potentially risky drug washouts – during which patients go off all medication – and placebo periods. However, much research involves a lower degree of risk, including protocols that offer subjects state-of-the-art evaluations that can help them manage their illness.

I was naturally apprehensive at the outset of the 1993 trial, I wondered if I would be assigned to the riskier arm of the study. As chance would have it, I was in the safer group and it went smoothly. At the time, though, I was convinced my psychiatrist placed me in the less risky arm of the trial. This is a common misperception, but, in fact, group assignment is completely random.

But as consumers we should be aware that research is not treatment. Many protocols may benefit participants, but that is not their primary purpose. The goal of research is the advancement of scientific knowledge. For that reason, well-informed consumers must ask researchers questions before and during the process.

It is also essential to feel safe and know that your participation is completely voluntary. Likewise, you should know that you have the right to leave a study at any time for any reason.

The very nature of mental illness can render us unable to comprehend a protocol's risk-benefit ratio, or cause us to mistrust researchers or to misperceive risk. Thus, it may be appropriate – even necessary – to involve family and friends when considering a research protocol. For example, the support and perspective of my family helped me complete my research trial and switch successfully to a new medication that stabilized me for eight years.

The possibility of relapse and the loss of decision-making ability also worries consumers. Having a durable power of attorney, or DPA, to make decisions on your behalf will ensure that your wishes are accomplished. Also important are advanced directives, contracts that allow volunteers to make choices in advance about their participation should their decision-making capacity be hindered.

With the proper protections in place, psychiatric research can be a rewarding experience for us as consumers. As partners with scientists and treatment professionals, we can be proud to be part of the discoveries that may lead to the eradication of mental illness in this century.

An Open Letter to My AMI Family:

Several years ago I became a HUD landlord in order to provide a home for a couple with mental illness who had a HUD voucher but no place to rent.

The process was simple and painless.

Now, as you know, rentals in San Diego County are expensive and hard to find. Because of this, many landlords with their eyes on the dollar are finding a way to evict HUD tenants so they can get higher rents. I don't have to tell you what a threat of homelessness means to our people.

The Housing Authority, which funds HUD tenants has countered by raising the "reasonable rent level" which it will pay, BUT, there are still so few rentals to be found that many of our people have to give up the HUD certificate they have waited years for, and continue to live in either a board and care, very sub-standard "cheap" housing, or even at home with you. When there are no openings in the Board and Cares, people who cannot be placed upon hospital or crisis house discharge are given a list of places to call on their own and often become homeless by default.

Would you like to help in a very significant way?

Here is something we can all consider. If you own any kind of rental property, you can easily become a HUD landlord. This includes anything: a trailer, studio, or multi-bedroom apartment or a house. Sorry, no rooms in boarding homes.

You will receive a very reasonable rent, part of it direct from HUD. Your first rental agreement can be for as little as six months. You have all the rights, including right of refusal, that landlords traditionally have. You will never lack for a tenant for as you know, our people are desperate for a place to live on their own. You have for them the additional advantage of knowing about mental illness and being sympathetic without sacrificing any of the ordinary expectations of a landlord.

Please contact me for details. We need to help our own. .If we don't, who will ?

Jane Fyer, (858) 481-7069

The Alliance Advocate

Vol. VI, Issue 4--April 2002



4480 30th Street
San Diego, CA 92116

Non-Profit
Organization
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San Diego, CA

RETURN SERVICE

Inside This Issue:

Participating in Psychiatric Research

A Home of Our Own

Legislative Update

Calendar of Events & Meetings

Being a HUD Landlord



NAMI San Diego

2002 MEMBERSHIP APPLICATION

NAMI San Diego relies on its membership and your generous contribution to continue providing support and services to people with mental illness and their families. To join NAMI San Diego, renew your membership or make a contribution, complete the information below and **enclose your check payable to NAMI San Diego and mail to: P. O. Box 710761, San Diego CA 92171-0761.**

Name: _____

Street: _____ Home Phone # _____

City, State, Zip: _____ Work Phone # _____

Dues are from January 1 to December 31 of each year and include membership and newsletter subscription to NAMI and NAMI California.

I would like to join NAMI San Diego at the following level:

- ____ Regular Membership – \$40.00 Check one: () New Member () Renewal
____ Professional Membership – \$75.00 (includes office display of NAMI brochures)
____ Consumer Membership – \$10.00 _____ Newsletter Subscription Only – \$15.00
____ Open Door Membership \$3.00 (consumer, consumer family & friends in financial need)

ANNUAL SUSTAINING DONORS

- ____ Bronze Donor – up to \$99.00 _____ Benefactor – \$500.00 – \$999.00
____ Silver Donor – \$100.00–\$249.00 _____ Patron – \$1,000 +
____ Gold Donor – \$250.00–\$499.00 _____ I prefer my contribution to be anonymous

Check relation to client:

- ____ Parent of Adult
____ Parent of child (under 18)
____ Sibling
____ Spouse
____ Professional
____ Other _____
____ Self

____ Please send me volunteer