



DRIVE FOR DIAGNOSIS 2026 GOLF CLASSIC

Benefitting the **CSNK2A1** Foundation &
TGEN'S CENTER FOR RARE CHILDHOOD DISORDERS

SPONSORSHIP PROPOSAL



APRIL 6, 2026
MONDAY



EL CABALLERO
COUNTRY CLUB
TARZANA, CALIFORNIA



How it all began.

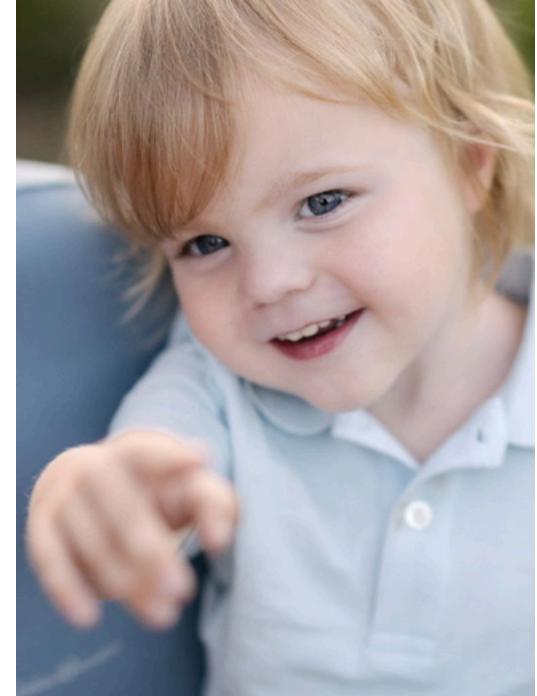
Okur-Chung Neurodevelopmental Syndrome (OCNDS) is an ultra-rare genetic disorder first identified in 2016. Although it is believed to affect thousands globally, only about 375 individuals have been diagnosed worldwide to date. In 2016, there were just five known cases, and no resources existed—no foundation, no website, no community, and no research.

In 2018, Jennifer and Jason Sills took action, founding the CSNK2A1 Foundation after their daughter became the 6th diagnosed case in the world. They created the foundation with a dual mission: to accelerate research for treatments and a cure and to provide a supportive community for families navigating OCNDS. Their work has since sparked hope, awareness, and progress, offering a lifeline to families affected by this rare condition.

What causes OCNDS?

OCNDS is a rare genetic disorder caused by a mutation in the CSNK2A1 gene. Individuals with OCNDS face significant challenges, including severe speech delays or the inability to speak, global developmental delays, epilepsy, traits of autism spectrum disorder, behavioral difficulties, and feeding problems. Everyday activities that many take for granted—such as swallowing, dressing, using the restroom, buckling a seatbelt, and making friends—are major hurdles for those living with OCNDS.

To navigate these challenges, individuals with OCNDS often undergo multiple therapies, including speech, occupational, feeding, and physical therapy, all of which can take hours each day. The journey for parents and caregivers is one of constant advocacy and sacrifice. They become not only caregivers but also advocates, nurses, champions, therapists, fundraisers, researchers, trailblazers, teachers, and paperwork experts—taking on roles they never imagined in order to provide the best care and support for their loved ones. The dedication of these families fuels the need for ongoing research and support, as they continue to seek treatments and a cure.



Why does funding OCNDS research matter?

The CSNK2A1 gene produces a protein called CK2, which is present in every human cell. In individuals with OCNDS, this protein is disrupted, leading to the many challenges associated with the syndrome. Our research aims to understand how to restore CK2 functionality in OCNDS patients, offering hope for more effective treatments. CK2 is not only a key protein for OCNDS, but it also plays a critical role in a variety of other serious diseases. By funding research into CK2's potential, we are not only advancing treatments for OCNDS but also contributing to breakthroughs that could benefit millions of people worldwide.

CK2 is being studied in relation to a wide range of conditions, including Parkinson's disease, Alzheimer's, autism, COVID-19, inflammatory diseases, ALS, cystic fibrosis, and cancer. A breakthrough in CK2 research for OCNDS could unlock new therapeutic possibilities for many other life-altering diseases

TGEN & CSNK2A1 Foundation Collaboration

TGen, part of City of Hope, is a nonprofit biomedical research institute focused on conducting groundbreaking research with life-changing results. In 2012, TGen established The Center for Rare Childhood Disorders (C4RCD) to harness the latest technological leaps in genomic sequencing to pinpoint the causes of rare childhood disorders and provide children and their families with a diagnosis and a path toward care and cures.

Through support from the CSNK2A1 Foundation and the Drive for Diagnosis Golf Tournament, TGen has established an OCNDS Research Program led by Dr. Matt Huentelman, the Scientific Director of TGen's C4RCD.

This partnership has allowed TGen and collaborators to deepen our understanding of the genetic changes that cause OCNDS and conduct foundational work to develop personalized therapeutic options.

The CSNK2A1 Foundation and TGen are moving quickly to the next stage of our research in which Dr. Huentelman's team is leading a study utilizing OCNDS patient-derived cells to determine how genetic mutations in the CSNK2A1 gene affect the function and structure of brain cells. We are proud to continue this partnership and advance our progress toward improved therapeutic options for those living with OCNDS.

This Year's Momentum: Your Dollar's in Action

Our research pipeline accelerated in remarkable ways. We celebrated **six new scientific publications**, including the first-ever paper from our OCNDS natural history study with Simons Searchlight. Our drug-repurposing program is advancing rapidly: **seven FDA-approved compounds are now being tested** across multiple animal models, with testing in cells donated by children with OCNDS beginning in 2026. These studies will identify which candidates have **real potential** to move toward clinical trials.

Our advocacy and infrastructure also strengthened this year. We submitted a formal request for an ICD-10 diagnostic code for OCNDS, now under review—an important step toward better care, better data, and better insurance access. We earned a **highly competitive \$125,000 PCORI Engagement Award** to build a patient- and caregiver-driven research agenda, and entered **Year Two of the Chan Zuckerberg Initiative Rare As One Program**, which continues to bring critical funding, tools, and training to our community.

Our July conference was our largest and most impactful yet. Nearly 200 attendees—including 25 families and 59 researchers and clinicians—came together to learn, collaborate, and set the top scientific priorities that will drive the next phase of discovery.

And our internship program continues to grow. We **welcomed 15 interns**, gaining hands-on experience in rare disease science, communications, and advocacy. Their creativity and energy are helping us scale faster and smarter than ever before.

**Every dollar counts.
You can make a difference today!**

THE IMPACT OF YOUR SUPPORT

Driving Discovery. Fueling Hope.



\$1.4M+

Raised from Drive for
Diagnosis Golf Tournaments



\$1.4M+

Invested in Research



16

Grants Awarded



13+

Labs working on
OCNDS/CSNK2A1



18

Quarterly Scientific
Roundtables



7

Family Conferences
(4 in-person & 3 virtual)



55

Family Support
Meetings



4

Scientific Conferences
(3 in-person & 1 virtually)



187

Individuals enrolled in the
OCNDS Natural History Study



371

Patients Worldwide



1

Biotech Partnership



30

Strategic Partners



15

Interns PHD & medical
trainees in 2025



7

FDA-approved drugs being
tested in our animal models



1

Compound being tested
in OCNDS mouse model

2026 Drive for Diagnosis Golf Classic

Benefiting the CSNK2A1 Foundation & TGEN's Center for Rare Childhood Disorders
Advancing research and hope for OCNDS families

Our Golf Committee

Leaders Driving Impact On and Off the Course

These leaders turn one day of golf into real progress for OCNDS families

Event Co-Chairs



Jennifer Sills
Founder,
CSNK2A1 Foundation



Micheal Kaplan, Jr.
TGEN Board Member

Committee Members



Tracy Phelps
Pinnacle Contracting
Corporation



Mike Grossman
CEO,
Pinnacle Contracting
Corporation



J. Michael Grossman
Chairman of the Board,
Pinnacle Contracting
Corporation



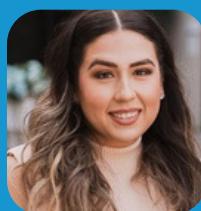
Jason Sills
J2 Properties, Inc.



Joey Behrstock
Paradigm Gilbert



Avisha Patel
Senior Counsel,
Southern California Gas
Company



Mariana Veyna
City of Hope



Mike Greenfeld
Co-founder,
Streamland Media



David Lebowitz
Partner
Watch Hill Capital

2026 Drive for Diagnosis Golf Classic

Tournament Schedule

Monday, April 6, 2026

El Caballero Country Club

18300 Tarzana Avenue Tarzana, CA 91356

(818) 654-3092



**8:00 AM-
10:00 AM**

Registration
Breakfast & Bloody Mary Bar
Massages
Smoothie/Coffee Bar
Putting Contest
Driving Range Opens

10:00* AM

Lucky few to chip for \$\$\$

10:30* AM

Shotgun Start
Four Person Team
Modified Best Ball Format
Exciting contests, food & drinks await you!

**4:00 PM-
6:00 PM**

After golf activities
Hosted Bar & Heavy Appetizers
Team/Contest Winners Presentation
Live Auction
Super Silent Auction
Opportunity Board prizes

***earlier start time again this year!**

2026 Drive for Diagnosis Golf Classic

Sponsorship Opportunities

Title Sponsor (SOLD! to PINNACLE CONTRACTING CORPORATION)\$30,000

As the Title Sponsor of the 2026 Drive for Diagnosis Golf Classic, your firm is assured high visibility before, during and after the Golf Tournament. Sponsorship includes:

- Sixteen (16) tournament playing spots, including tee gift bags
- Sixteen (16) additional reservations for the Awards Cocktail Reception
- Listed as Title Sponsor of event on all printed material and event signage
- Corporate name mentioned in any event promotion
- Special recognition at Awards Dinner-company representative invited to speak during program
- Name recognition on event promotional banner plus one corporate banner prominently displayed at the tournament
- Six (6) on-course tee signs
- Two (2) souvenir Pin Flags with your company logo displayed at a hole during tournament
- Full-page acknowledgment in virtual Event Program
- Opportunity to display promotional material and/or provide product samples on day of event to all players in gift bags
- Recognition of your company on both the CSNK2A1 Foundation & TGen social media

Presenting Sponsor (1 SOLD!)\$17,500

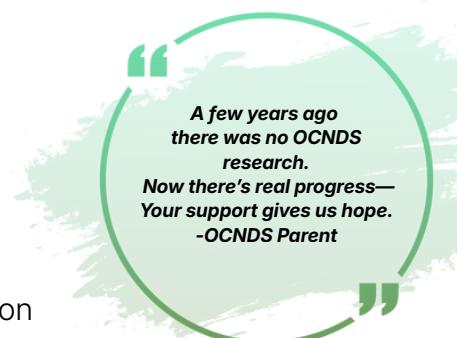
As a Presenting Sponsor of the 2026 Drive for Diagnosis Golf Classic, your firm is assured high visibility before, during and after the Golf Tournament. Sponsorship includes:

- Twelve (12) tournament playing spots, including tee gift bags
- Six (6) additional reservations for the Awards Cocktail Reception
- Corporate name mentioned in any event promotion
- Name recognition on event promotional banner
- One corporate banner prominently displayed at the tournament
- Four (4) on-course tee signs
- One (1) souvenir Pin Flag with your company logo displayed at hole during tournament
- Recognition of your company on both the CSNK2A1 Foundation & TGen social media
- Full-page acknowledgment in virtual Event Program

\$12,500 Sponsorship Opportunities

Major Tee Gift Sponsor (One Available)

- Eight (8) tournament playing spots, including tee gift bags
- Four (4) additional reservations for the Awards Cocktail Reception
- Name recognition on event promotional banner
- Three (3) on-course tee signs
- One (1) souvenir Pin Flag with your company logo displayed at hole during tournament
- Recognition of your company on both the CSNK2A1 Foundation & TGen social media
- Full-page acknowledgment in virtual Event Program



Caddie Sponsor (One Available)

- Eight (8) tournament playing spots, including tee gift bags
- Four (4) additional reservations for the Awards Cocktail Reception
- Name/logo recognition on the back of the caddie bibs worn at tournament
- Three (3) on-course tee signs
- One (1) souvenir Pin Flag with your company logo displayed at hole during tournament
- Recognition of your company on both the CSNK2A1 Foundation & TGen social media
- Full-page acknowledgment in virtual Event Program

\$11,000 Sponsorship Opportunity

Awards Cocktail Sponsor (SOLD!)

- Four (4) tournament playing spots, including tee gift bags
- Eight (8) additional reservations for the Awards Cocktail Reception
- Company banner displayed at dinner
- Recognition at dinner from MC
- One (1) on-course tee sign and one (1) easel sign at dinner
- One (1) souvenir Pin Flag with your company logo displayed at hole during tournament
- Recognition of your company on both the CSNK2A1 Foundation & TGen social media
- Full-page acknowledgment in virtual Event Program

\$8,000 Sponsorship Opportunities

Sign Sponsor (One Available)

- Flag Four (4) tournament playing spots, including tee gift bags
- Flag Four (4) additional reservations for the Awards Cocktail Reception
- Flag Company logo/name recognition on all tournament tee signs
- Flag Two (2) on-course tee signs
- Flag One (1) souvenir Pin Flag with your company logo displayed at hole during tournament
- Flag Recognition of your company on both the CSNK2A1 Foundation & TGen social media
- Flag Full-page acknowledgment in virtual Event Program

Golf Cart Sponsor (One Available)

- Flag Four (4) tournament playing spots, including tee gift bag
- Flag Four (4) additional reservations for the Awards Cocktail Reception
- Flag Two (2) on-course tee sign
- Flag Signage on all of the golf carts (approx. 60) used in the tournament
- Flag One (1) souvenir Pin Flag with your company logo displayed at hole during tournament
- Flag Recognition of your company on both the CSNK2A1 Foundation & TGen social media
- Flag Full-page acknowledgment in virtual Event Program

\$6,250 Sponsorship Opportunities

Executive Sponsor (Multiple Available)

- Flag Four (4) tournament playing spots, including tee gift bags
- Flag One on-course tee sign
- Flag Half-page acknowledgment in virtual Event Program



\$3,125 Sponsorship Opportunities

Beverage Sponsor (Five Available)

- ▶ Two (2) tournament playing spots, including tee gift bags
- ▶ Signage at one beverage station
- ▶ Recognition in virtual Event Program

Contest Sponsor (Five Available)

- ▶ Two (2) tournament playing spots, including tee gift bags
- ▶ Signage at one contest hole
- ▶ Recognition in virtual Event Program

Each Playing Spot includes:

- Full Breakfast & Drinks
- Golf, golf cart & group caddie
- Player tee prize
- Driving range balls
- Lunch
- Hosted cocktails
- Heavy appetizers for Awards Cocktail Reception

Limited individual golf spots available for \$1,600.00 -

Please contact Robert Ward **bertward@roadrunner.com** or Bob Levey at **bob@iemgolf.com** or **818-264-6893**.



Harper is non-verbal &
uses a communication device
to communicate.
We hope to find our
daughter's voice.



Non-Golf Sponsorship Opportunities

\$2,000 Sponsorship Opportunities

Massage Therapist Sponsor (One Available)

- Sponsor the appearance of massage therapists, who will offer neck & shoulder massages or stretching during the tournament
- One (1) on-course tee sign at massage hole
- Recognition in virtual Event Program
- Two (2) tickets to the Awards Cocktail Reception



Golf Ball Sponsor (One Available)

- Sponsor 35 dozen golf balls distributed to tournament players as part of player gift package
- Company name/logo on 35 dozen golf balls
- Signage at tournament recognizing your sponsorship
- Recognition in virtual Event Program
- Two (2) tickets to the Awards Cocktail Reception

“

Our daughter can live seizure-free & have better quality of life.

Bloody Mary Bar Sponsor (One Available)

- Sponsor tournament Bloody Mary drinks served during Breakfast to players at tournament
- Signage at the Bloody Mary Bar recognizing your sponsorship
- Recognition in virtual Event Program
- Two (2) tickets to the Awards Cocktail Reception

Chip-Off Sponsor (One Available)

- Sponsor the exciting pre-tournament Chip-Off Contest from the 9th fairway, where selected players will each have a chip for a chance to win up \$\$\$
- Signage on at Chip-Off site at tournament (9th green before tournament)
- Recognition in virtual Event Program
- Two (2) tickets to the Awards Cocktail Reception

Non-Golf Sponsorship Opportunities

\$1,500 Sponsorship Opportunities

Golf Ball Launcher Sponsor (One Available)

- ▶ Sponsor the Hot Shot Cannon, an exhilarating golf ball launcher that promises golfers a fun and unforgettable experience, bringing them closer to the green with their first shot
- ▶ Signage at tournament recognizing your sponsorship
- ▶ Recognition in virtual Event Program
- ▶ Two (2) tickets to the Awards Cocktail Reception

Smoothie/Iced Coffee Truck Sponsor (One Available)

- ▶ Sponsor the Smoothie/Iced Coffee Truck that will serve players drinks throughout the day
- ▶ One (1) tee sign at turn area where truck is located
- ▶ Recognition in virtual Event Program
- ▶ Two (2) tickets to the Awards Cocktail Reception

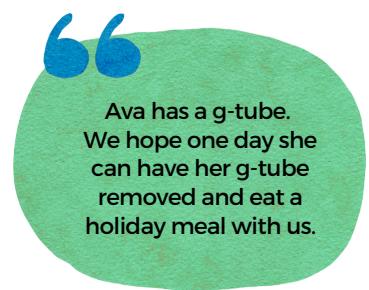


Cigar Sponsor (One Available)

- ▶ Cigar company will set up at tournament and hand-roll cigars for players
- ▶ Signage at cigar station recognizing your sponsorship
- ▶ Recognition in virtual Event Program
- ▶ Two (2) tickets to the Awards Cocktail Reception

Breakfast Burrito (One Available)

- ▶ Sponsor the famous and beyond delicious Drive for Diagnosis burritos served to players during breakfast at tournament
- ▶ Signage at breakfast recognizing your sponsorship
- ▶ Recognition in virtual Event Program
- ▶ Two (2) tickets to the Awards Cocktail Reception



On Course Hosted Bar Sponsor (Two Available)

- ▶ Sponsor tournament cocktails served to players at the turn during tournament
- ▶ Signage at the bar recognizing your sponsorship
- ▶ Recognition in virtual Event Program
- ▶ Two (2) tickets to the Awards Cocktail Reception

Non-Golf Sponsorship Opportunities

\$1,000 Sponsorship Opportunities

Tee Box Sponsor (Multiple Available)

- ▶ Host and own one tee box on the course
- ▶ Opportunity to offer a service or product sample to all golfers
- ▶ Signage at sponsored tee box
- ▶ Recognition in virtual Event Program
- ▶ Two (2) tickets to the Awards Cocktail Reception



\$750 Sponsorship Opportunities

19th Hole Reception Bar (One Available)

- ▶ Sponsor tournament cocktails served to players after the tournament
- ▶ Signage at the bar recognizing your sponsorship
- ▶ Recognition in virtual Event Program
- ▶ Two (2) tickets to the Awards Cocktail Reception

Hole in One Sponsor (Four Available)

- ▶ Sponsor one of the four Par 3 Hole in One Contests that the golfers will attempt to win
- ▶ golf trips and prizes by making a hole in one
- ▶ Tee sign at one (1) Par 3 hole as Hole in One sponsor
- ▶ Recognition in virtual Event Program
- ▶ Two (2) tickets to the Awards Cocktail Reception

\$500 Sponsorship Opportunities

Tee/Green Sponsor (Multiple Available)

- ▶ Company signage at sponsored tee
- ▶ Recognition in the virtual event program

\$350 Sponsorship Opportunities

Full-page Acknowledgement in Virtual Event Program (Multiple Available)

- ▶ Full-page acknowledgment (company or personal) in virtual Event Program

2026 Drive for Diagnosis Golf Classic

To benefit the CSNK2A1 Foundation & TGEN's CENTER FOR RARE CHILDHOOD DISORDERS in their collaborative efforts to diagnose and find a cure for Okur-Chung Neurodevelopmental Syndrome

El Caballero Country Club Monday, April 6, 2026

Gifts and Prizes

We are seeking items in various categories for our annual Golf Classic fundraiser.

We request items for the following categories:

Player Tee Gifts:

Quantity requested is 144 to accommodate all golfers-with your company logo

Opportunity Board/Live Auction:

Gifts to be used for the day of event fundraising

Company:

Contact Person:

Address:

City:

State:

Zip:

Phone:

Fax:

Email:

Item(s) to be donated:

Tee Gifts:

Value (each):

Opp. Board/Auction:

Gift Value (each):

Restrictions or Timelines:

Please check where appropriate:

- Coupon(s) / certificate(s) are attached
- Item(s) will need to be picked up (please call the number below to arrange pickup)
- Item(s) will be shipped on (date)

Signature: _____ Date: _____

Please return this form to: Jennifer Sills
at golfclassic@csnk2a1foundation.org
(415) 501-0147

2026 Drive for Diagnosis Golf Classic

To benefit the CSNK2A1 Foundation & TGEN's CENTER FOR RARE CHILDHOOD DISORDERS in their collaborative efforts to diagnose and find a cure for Okur-Chung Neurodevelopmental Syndrome

El Caballero Country Club Monday, April 6, 2026

Golf Entry Form (Page 1 of 2)

Company Name: Name:

Email: Phone Number:

- Sorry, I can't play but I want to participate and support this important program - enclosed is my donation.
- I have made an online donation.
- Yes! I would like to register for this year's Golf Classic

***Please check appropriate sponsorship(s):**

<input type="checkbox"/>	Title Sponsor (SOLD!)	\$30,000
<input type="checkbox"/>	Presenting Sponsor (1 SOLD!)	\$17,500
<input type="checkbox"/>	Major Tee Gift Sponsor\$12,500
<input type="checkbox"/>	Caddie Sponsor	\$12,500
<input type="checkbox"/>	Awards Cocktail Reception Sponsor (SOLD!)	\$11,000
<input type="checkbox"/>	Sign Sponsor	\$8,000
<input type="checkbox"/>	Golf Cart Sponsor	\$8,000
<input type="checkbox"/>	Executive Sponsor	\$6,250
<input type="checkbox"/>	Beverage Sponsor	\$3,125
<input type="checkbox"/>	Contest Sponsor	\$3,125
<input type="checkbox"/>	Individual Playing Spot...	\$1,600

NON-GOLF SPONSORSHIPS

<input type="checkbox"/>	Massage Therapist Sponsor	\$2,000
<input type="checkbox"/>	Golf Ball Sponsor	\$2,000
<input type="checkbox"/>	Bloody Mary Bar Sponsor	\$2,000
<input type="checkbox"/>	Chip-Off Sponsor	\$2,000
<input type="checkbox"/>	Golf Ball Launcher Sponsor	\$1,500
<input type="checkbox"/>	Smoothie/Iced Coffee Truck Sponsor	\$1,500
<input type="checkbox"/>	Cigar Sponsor	\$1,500
<input type="checkbox"/>	Breakfast Burrito Sponsor	\$1,500
<input type="checkbox"/>	On Course Bar Sponsor	\$1,500
<input type="checkbox"/>	Tee Box Sponsor	\$1,000
<input type="checkbox"/>	19th hole Cocktails Sponsor.....	\$750
<input type="checkbox"/>	Hole in One Sponsor.....	\$750
<input type="checkbox"/>	Tee/Green Sponsor.....	\$500
<input type="checkbox"/>	Full-page acknowledgment in virtual Event Program	\$350

Enclosed is my check for \$..... made payable to: CSNK2A1 FOUNDATION

Submit payment to: CSNK2A1 Foundation c/o Golf Classic, 1395 Marsten Rd. Burlingame, CA 94010

2026 Drive for Diagnosis Golf Classic

To benefit the CSNK2A1 Foundation & TGEN's CENTER FOR RARE CHILDHOOD DISORDERS in their collaborative efforts to diagnose and find a cure for Okur-Chung Neurodevelopmental Syndrome

El Caballero Country Club Monday, April 6, 2026

Golf Entry Form (Page 2 of 2)

Sponsorship Contact Name: Phone Number:

Sponsoring Company: Email:

Name (player #1)

Company: Daytime Phone:

Address: Fax:

City: State: Zip:

Handicap/Index: Email:

Name (player #2)

Company: Daytime Phone:

Address: Fax:

City: State: Zip:

Handicap/Index: Email:

Name (player #3)

Company: Daytime Phone:

Address: Fax:

City: State: Zip:

Handicap/Index: Email:

Name (player #4)

Company: Daytime Phone:

Address: Fax:

City: State: Zip:

Handicap/Index: Email:

Please photocopy or request additional player information forms if needed.

Please return this form to: IEM at bob@iemgolf.com 818-264-6893

Or register online at: <https://www.csnk2a1foundation.org/golf-tournament>

*For golf tournament inquiries, please contact Robert Ward at bertward@roadrunner.com or Bob Levey at bob@iemgolf.com or 818-264-6893 (cell).



Drive for Diagnosis 2026 Golf Classic



2026 Drive for Diagnosis Golf Classic

To benefit the CSNK2A1 Foundation & TGEN's CENTER FOR RARE CHILDHOOD DISORDERS in their collaborative efforts to diagnose and find a cure for Okur-Chung Neurodevelopmental Syndrome

TO SIGN UP FOR TOURNAMENT SPONSORSHIPS OR DONATIONS:

01: Please donate online at
<https://www.csnk2a1foundation.org/golf-tournament-2026>

02: Mail donation to: CSNK2A1 Foundation
1395 Marsten Rd. Burlingame, CA 94010

03: Print out sponsorship commitment forms, scan, and email to golfclassic@csnk2a1foundation.org

04: We will contact you for your Company Logo and information for Sponsorship recognition

05: Email your Golf Player information sheet to bob@iemgolf.com once you have secured your players.

Scan Me



 **CSNK2A1**
FOUNDATION